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NAT-CENT NEWS

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EDITORIAL: IN RETROSPECT

By Robert J. Smithdas, LHD, Litt.D, LHD

Now that we have completed the first full year of a new century and a new millennium, it seems appropriate to review the progress that has been made in providing much needed programs as well as aids and devices for deaf-blind citizens in the United States. The last fifty years of the twentieth century in particular, brought tremendous changes in rehabilitation and training programs for all disabled people. A host of new technologies were developed (and are still developing) to help disabled people overcome the limitations of their disabilities through use of assistive devices and technologies that today provide disabled individuals with a growing sense of independence.

When I began attending St. John's University in September of 1947, the Perkins Brailler was not yet on the market. There were no braille displays for computers, and computers were huge machines used only by professional workers. Transcribing textbooks into braille was done by hundreds of dedicated volunteer transcribers who used board slates and styluses, punching out the letters of the text a dot at a time. My own college textbooks had to be ripped into sections and sent to transcribers all over the country to be copied into braille, tediously, by hand.

I was probably the first deaf-blind person to learn to travel with the long cane developed by Dr. Hoover of the Veteran's Administration after World War II. It was not until the mid-seventies that Mowat sensors, laser canes and various other electronic mobility devices came into being.

When I first moved into my own apartment in 1956, there were no convenient vibrating signaling devices to let one know if the doorbell or telephone were ringing. You had to use your creative sense to solve such problems. At that time, there were also no pagers, CCTV's or telecommunication devices except for crude, barely functional, homemade inventions. Rehabilitation centers and services were just beginning to flourish in the late 1950's.

Today, students have the benefit of attending centers like the Helen Keller National Center to learn the latest advancements in all services available to them, usually at state expense and sponsorship. They are indeed fortunate to have equal access to such sources of assistance. Personally, I never attended a formal rehabilitation program, and what I had to learn came from actual experiences or from observing others who had already made their adjustments to being deaf-blind.

For disabled people, the past fifty years have been a golden age of progress in research and development and consumer benefits. No doubt the future will bring new opportunities for us to use our skills and talents to achieve success, and we should be ready to accept the changes as they come.

DO YOU WANT TO GO SAILING?

Have you always wanted to go on a cruise? Would you like to join us, see old friends, and make new ones?

Here is your chance. Right now we are formulating a plan for our very first Deaf-Blind Caribbean Cruise ever! The tentative date is May 2002. If the demand exists, we will have biannual cruises.

Don't miss our seven nights of fun, entertainment, games and relaxation. Platform interpreters, tours of the ship, large print and braille menus, TTY's and volume control phones in each room, a loop for the shows, a dog guide walker and insurance will all be included in the package.

The estimated cost for each person is

$1,300. (plus airfare) for double occupancy, and $900. (plus airfare) for three or four in a room. We will know more details at a later date.

The first deposit for each person will be due in February 2001, in the amount of $100. (or $300. to reserve a cabin near the elevators in the middle of the ship.) If interested, payment arrangements can be made.

For more information, please contact: Lynn Jansen, 4100 Harrison Avenue, Cincinnati, OH 45211. (513)662-0674 (voice) or E-mail LynnSmilin@aol.com or LAKTS@aol.com

I COULDN'T SEE A THING...

By Heather Allen

(Editor's Note: Heather Allen is the sister of Matthew Allen who was a student at the Helen Keller National Center in the PATH

Program.)

Thank God, I am finally out of that dark and murky place. I see strange things that are new to me. I see blurs, light and other unidentifiable things. The glares begin to become clear but I am short of breath. What is happening! These wonderful objects are slowly fading away. Shorter and shorter becomes my breath. There! There were the lights again. And my breath is suddenly back. The sights I briefly saw vanished along with my hearing that is sluggishly withering as well.

My mother! Her voice fades away along with all the foreign sounds in the room. The momentary comfort that her warm voice brought is gone. Dead. I can hear and see nothing. I must depend on my senses of taste, touch and smell, without the help of the other two.

The feathery softness of the wonderful bed I was lain on soothes my fears and helps to ease the pain of hard tubes entering my throat. My mother's hands caress me and make me feel so tranquil. I open my eyes, but see nothing. Hurt spreads through my eyes and ears as I can only feel the warmth of my mother's delicate hands and the blaze behind my sight gates, which are locked up forever.

Hello! Is anyone there? Can anyone hear me? Where are they, my brothers, sister, and mother? We once stood shoulder to shoulder, stretching out, touching, entwined in each others embrace. We bathed in the warm sunlight; the life giving light I never saw. We shivered in the ice and snow; but we had each other. Where are they now? Darkness and silence blanket me and nothing stirs, only me.

Reaching out, blindly, as far as I can, I touch nothing. I don't know how or why this is happening, but it frightens me. I need someone! Touch me so I know you're there. There once were voices and people but I can't remember that anymore. No voices now. Where are they? Gone?

I scream at the void. No one seems to hear me or even care. I can't even hear myself. There! Something, I felt it. A vibration, a movement, yes there it is again. It comes closer but it is alien to me. I cannot understand where everything has gone. This is so close I can almost touch it. The pulsation is vibrating my body for the sight and sound I once briefly had. I can't take the pain anymore. Get this out of my head! I need my family, familiar scents or anything to comfort the pain. As the pain sears through me, I shudder. My silent cry shatters the blue sky and the torment blinds me to the sunlight I've never seen. But then again, what is sunlight?

I fall, my knees crashing to the ground, hoping to feel or smell something to relieve my agony. The vibrations return and a force pins me down to a coarse, elevated, yet padded surface and a sharp implement pierces the skin of my arm. Soon, the warm, comforting touch returns and my hurtful sensations bleed away as my life force soaks into my mother's arms. Awaiting sleep, I pray to postpone the pain as long as possible, but after my rest tonight, everything will return, hurt and suffering as well. I drift off, slowly, to a world where everything is warm, yet blurred, as were the first few minutes of my life.

LYNN JANSEN: VISION FOR HERSELF AND HER DEAF-BLIND GROUP

By Deborah Kendrick

(Editor's Note: Deborah Kendrick is a nationally recognized advocate for people with disabilities. She can be reached at the Cincinnati Enquirer, Cincinnati, OH)

When Lynn Jansen was a 3-year-old nursery school student at Cincinnati Speech and Hearing, she received her first hearing aids. By the time she was a student at Seton High School, she knew she had a vision problem too. She would be in her 30's before the name of the hereditary condition affecting three of her mother's nine children was known to her - Usher syndrome.

Three to six percent of children born with hearing impairments can be expected to have Usher syndrome, a condition that involves both hearing loss and retinitis pigmentosa, a progressive eye disease that often leads to blindness. Three types of Usher syndrome have been identified. Ms. Jansen says she is one of the lucky ones - her hearing loss has stabilized, her vision loss is progressing more slowly than some, and she has no balance difficulties.

Seven years ago, Ms. Jansen joined a group that meets quarterly in Columbus. Through involvement with the Ohio Deaf-Blind Outreach Program, she and her friend, Nellie Pohlmeyer, another Cincinnatian with

Usher syndrome, found themselves in the role of key organizers for a national conference held recently in Columbus.

The AADB (American Association of Deaf-Blind) is for people with all kinds of hearing and vision impairments, Ms. Jansen explains. "I'm low-vision/hard of hearing. Some are totally deaf, totally blind. Some are deaf and legally blind. All of us are different."

As workshop coordinator, Ms. Jansen put in 8 to 10 hour days for several months. Martial arts gold medalist, Tokey Hill, led six sessions of deaf-blind delegates in self-defense lessons. Massage therapists were on hand for relieving the tension of tactile interpreting for both deaf-blind consumers and their interpreters. Sessions also included training guide dogs for deaf-blind individuals, using the Internet to find a job, and training qualified interpreters.

Organizing any conference is hard work, but when all involved have some level of vision and/or hearing impairment, flexibility is the operative word. To set up workshops, Ms. Jansen communicated via telephone (she is part of what's called the deaf-blind speaking group), TTY, e-mail, conventional mail, and deaf relay services (in which an operator types spoken conversation to a deaf person, and speaks typed comments back to the one able to hear.)

Lynn Jansen and Nellie Pohlmeyer take these ways of talking to people for granted. At the conference, communication occurs in almost as many forms as there are people. Those who have sufficient vision read lips, follow the motions of a sign language interpreter, or pull a chair in close range to read the verbatim transcript of discussion being typed (in 2 inch characters) on video monitors. Then, there are the clusters of people around the room with limited vision, huddled close to see an interpreter who is repeating the words of a presenter on stage and, finally, the many pairs of one-on-one in which tactile interpreters are signing directly into the hands of participants who are totally deaf-blind.

Ms. Jansen takes the challenge in stride. The Cheviot single mother of three has been chasing challenges all her life. Five years ago, she decided she was too smart to be an accounting clerk all her life and returned to college. In May she graduated with an accounting degree from the College of Mount St. Joseph where she says accommodations to students with disabilities are magnificent. She'll be job hunting now, but her work with AADB is far from over.

Ms. Jansen and Mrs. Pohlmeyer plan to begin a deaf-blind social group in Cincinnati. Many people who have some sight or some hearing don't realize that they could benefit by identifying themselves as deaf-blind. To better communicate with their signing friends, the two women have arranged an accommodation in an ASL class at Cincinnati State - a second interpreter repeats up close for them the signs being taught by the teacher they are unable to see.

Adaptation and imagination are key to living full lives with disabilities as demonstrated by Ms. Jansen in raising her teenagers, going to school, and organizing. Ms. Pohlmeyer says it all when she explains that her new job, at 56, in working in her husband's Backstage Deli downtown is to run the cash register and flirt!

DEAF, BLIND AND LIVING LIFE TO THE LIMIT

(From the newsroom of the Telegraph, United Kingdom)

Graham Hicks loves dangerous sports and is determined his disabilities won't stop him.

No one can accuse Graham Hicks of being

a sissy. The double garage at his home in Peterborough is stuffed with big-boys' toys. A three-seater jet ski capable of 60 miles per hour stands in one corner, gleaming from a recent outing on the Norfolk coast. Water-skis, wet suits and climbing ropes hang from the roof alongside rows of power tools and gadgetry. Tucked between a banana boat and a brace of tandem racing cycles is the pride of his collection - a souped-up quad bike.

Deaf and blind since childhood, Graham, 38, has never let his disabilities get in the way of his passion for speed and he is already training for his next big challenge - crossing the English Channel on a jet ski.

"I like moving fast, and basically the rougher the ride, the more fun it is," he says, crossing brawny arms over a broad chest. He was registered blind at three, and was profoundly deaf by seven, but he can still enunciate, unlike those who are born without hearing.

Throughout our conversation, Monica Evans, his interpreter, constantly fingerspells into his hand. Graham can talk but he "hears" through touch. "I love to push myself to the limit," he says. "I don't get anxious because if I tense up I will just hurt myself more when I take a corner too fast and I'm catapulted into the air." Jackie, his wife, who is sitting nearby, grimaces at the thought.

Jackie, who is chief executive of the charity Deafblind UK, met Graham, who is a director, four years ago. They married in May 1999. She admits laughingly that she has long since given up trying to persuade her husband to take up gentler pursuits. She even rides along on many of Graham's high-horsepower forays. He needs someone to ride with him at all times to give him directions and warn him of hazards.

"There is no point in me worrying about his sports activities, because they are terribly important to him," she shrugs, sipping a cup of strong coffee. "I can see him getting agitated if he hasn't had a fix of speed or danger for a while. But it is a bit of a strain because there are so many obstacles."

Chief among them is the widespread assumption that deaf and blind people must be a danger to themselves and others.

The French port authorities have still not agreed to let Graham make his Channel crossing, calling into question his ability to drive a jet ski. Meeting him, it is hard to think of him as incapable, especially when he starts revving up his electric saw for a spot of carpentry.

"I am very determined, and you have to be positive," he says. "Of course, the world does not go round for you but it does get annoying after a while. After all, how many people do you know who can drive a jet ski? How many people can re-wire the entire house, like I am doing?"

Graham was recently refused a cash card

from his bank on the grounds that "deaf and blind people don't go shopping."

If the general public needs to show a little more understanding, the government also has a role to play. It has been accused of overlooking the 20,000 or more in the deafblind community. And although there are provisions for people who are deaf and people who are blind, those with both disabilities seem to be in limbo.

"The government has set up the Disability Rights Commission but we don't yet know if it will be effective," says Jackie. "From our experience, deaf and blind people are at the bottom of the pile."

Graham has been assigned an interpreter by Deafblind UK and Jackie is adept at finger-spelling but many others have no access to this service. "A lot of people with Graham's ability and potential are forced to sit at home all day because they do not have any support," says Jackie.

Despite the difficulties of being both blind and deaf, Graham is determined to be positive. He has a supportive family, including three step-children, Tom, 19, Michael, 17, and Aniki, 12. He can afford a special braille computer which allows him to keep in touch with friends and access the worldwide web. He enjoys reading his large collection of poetry, and his special braille edition of The Oxford English Dictionary runs to 16 volumes.

Graham's disability brings benefits to their marriage, Jackie says - it makes their relationship more honest. "You can't play games, which is good overall because you have to be honest with one another."

There are moments when other people's insensitivity hurts. Jackie recalls rude interruptions to dinner dates. "I might be signing on Graham's hand and people will come up and ask if I am a volunteer. They don't seem to understand that we might be man and wife on a romantic night out. It's little things like that which get you down."

Mischa Scorer, producer and director of the television program, Deafblind, which features Graham and Jackie alongside others, agrees that life can be hard for people without hearing or sight. "For these people, the world means nothing unless you can touch it with your hands. I now recognize what a completely alien world they live in."

His admiration for Graham Hicks is boundless. "Graham is phenomenal. He is the sort of person who would have achieved something enormous in his life, whatever happened."

A BRIGHT LIGHT IN THE DARKNESS

By Lyndsay Sutton

(Reprinted from the Glasgow Daily Times, Glasgow, KY)

Brian Stockard sat perched on the edge of a love seat in the Glasgow Days Inn lobby while his seven-year old "sister," Racheal, lay behind him, sometimes curled up in a ball, sometimes stretching out along the seat cushions like a contented cat. There seems to be an inexpressable comfort in being near her "brother."

In between filling and refilling a white styrofoam cup with water, Racheal's dad, Dave Arredondo, relaxed in a chair diagonal from his "son." Dave is aware of how thirsty Stockard gets when he talks at length; the cup is never empty for more than a couple of seconds.

It is nearly a quarter to midnight and they have been traveling for 3 days at no more than 30 miles per hour and no less than 15 mph, but Stockard and his "family" have finally reached their third overnight destination, Glasgow. The Arredondos, 8 in all, and Stockard left South Bend, Indiana, Monday morning beginning a 1,200-mile bicycle trek to Old Town, Florida.

"Brian's Challenge," as the journey is called, is a quest for many things, one of which is to gauge Brian's limitations.

A quick glance shows a young black man, wearing a red "Just Do It" t-shirt, conversing with a middle-aged white man while a sleepy little girl rubs her eyes and nibbles on cheese and peanut butter crackers.

An extended glance reveals that Stockard rarely makes direct eye contact with anyone else in the room. He is not shy, looking over your head or concentrating on the ground. He is rather attentive, his eyes always summoned by the sound of a voice.

Chances are that when his eyes come to rest on someone else's he can't see them anyway. At best, they are a chameleon-like blur, merely blending in with the greens and blues of a chair.

Stockard's vision is 20/00 in one eye and 20/400 in the other. The poor eyesight is half of the Usher syndrome he has been diagnosed with since age 15 which could eventually lead to tunnel vision and blindness.

The other half of Usher syndrome is in the form of 2 hearing aids; Stockard has just 10 percent of his hearing. Now 30, the deaf-blind man wasn't expected to live past age 5.

Twenty-five years later and 355 miles from the place he calls home, Stockard is the portrait of a person so genuine and hopeful, so delightful and strong, you vow never to complain again about not having enough time in the day or making excuses even if there were.

Stockard rides one of his 3 bikes

sandwiched between Dave's van and Barbara Arredondo's Trans-Am anywhere from 100 to 150 miles a day on non-major highways and back roads to stay on schedule. Though they communicate with two-way radios, Stockard, who also wears a headset, depends largely on the yellow lines - well, blurs - on the road.

"I'm always challenging myself to do something new," Stockard said. "It's like I'm trying to find out my limitations. I want to see how far I can go, all the things I can do. And so far, I haven't reached a limitation yet."

Unless his body physically gives out in exhaustion, Stockard's well of limitations will likely remain empty. He continually draws inspiration and encouragement from the words of his late father who lost his right arm and leg after falling from a railroad car.

Throughout his life, relatives expressed doubt about what things he could do because of his disabilities. If he couldn't see and he couldn't hear, what could he possibly do and how could he possibly take care of himself?

"All the negativity that I grew up around kind of grew on to me and I nearly gave up on wanting to trying anything at all," Stockard said. "And it had been one person who actually kept that light going, who kept that spirit up and that was my father."

"His father instilled in him if you want something, and you want it bad enough, you can do it," said Stockard's neighbor, Bill Borders.

Borders and his wife, Jean, serve as home base for the trip, staying in touch with the Arredondos and Stockard on as regular a basis as possible. Though a cellular phone battery was accidentally left behind in an Indianapolis hotel room, the two families communicate at least every night when Stockard and the Arredondos stop for the evening.

Stockard has known the two families for nearly 8 years. When Stockard moved to

South Bend 9 years ago, he moved into the same apartment building as Dave and Barbara and the Borders' daughter, Dee.

Over the years, Stockard has become a permanent fixture in each of their homes. After his work as a dishwasher at the Chicago Steak House is done on Saturday nights, Stockard bikes to Dave and Barbara's to spend the night and go to church the next day.

When Racheal was first born, a babysitter from upstairs kept her while the parents were out. Stockard, who lived across the hall, was on his way out one night when he heard Racheal crying. The babysitter couldn't calm the baby down so Stockard asked to hold her. Immediately, she stopped crying.

"And ever since then, he and my daughter have been so close," Dave said. "My daughter calls him 'brother.'"

Stockard has often babysat for the Borders' grandchildren in the past and once had a paper route with one of their grandsons.

"Like anybody else, the first time my daughter told me he was gonna babysit, I cringed. I mean, how's he gonna see? How's he gonna hear?" Jean questioned.

She doesn't question anymore. Not only does he knit baby clothes and blankets in his spare time but he once built a bike for Jean with spare parts. He does his own grocery shopping except when he has to pick up cat food and litter for his 3 cats; those bags are too big for him to carry on his bike.

Stockard relies heavily on his computer. He has special equipment that enlarges everything so that one letter takes up almost the entire screen. When his computer isn't working, he goes to the library where Jean works and they have special equipment there to help him.

He designed a flier and the t-shirt logo for the trip using his personal computer. He's interested in pursuing a career as a webpage designer. He washes his own clothes and he loves to cook and experiment with different dishes. He is known to invite his deaf friends over for dinner.

Several summers ago, he painted his house with Jean and Bill merely pointing out the spots he missed. "He does more with his handicap than most people who don't have any physical ailments," Bill said.

Even so, the families still worry about him traveling on the roads, without being able to see or hear very well. "I worry about him on this trip," Bill said. "I'll probably get 2 or 3 more gray hairs before he gets back."

A near run-in with a tractor-trailer was the numbing lump that stuck in all of their throats. Stockard's uncle, Daryl, riding from South Bend back to his home in Indianapolis, informed his nephew that a truck was coming down the road and he should move over to the right. But when Stockard moved to the right, the truck did too, so Stockard was told to veer back to the left.

In the midst of his confusion, Stockard didn’t realize the truck had come within 6 or 7 feet of hitting him.

"Racheal told me right then. ‘Dad, we’ve got to stop because I don’t want anything to happen to my brother,’" David said.

The caravan didn’t stop even though it shook them all. Stockard has one thing on his mind and that’s making it to Old Town, Florida. As far as anybody knows, he is the first deaf-blind person to even attempt something like this, much less follow through with it.

What began as a joke between Dave and Stockard about riding a bike 90 miles to the nearest White Castle has evolved into Stockard’s quest to raise awareness about deaf-blind people and to raise money for the non-profit organization, the Helen Keller National Center for the Deaf-Blind Youths and Adults.

"I just want the opportunity for deaf-blind people, just people, to realize that we're not in the dark," Stockard said. "Although we may see darkness, we've still got a light there that gives us strength to survive independently."

Stockard will spend extra time in Atlanta with a sister's family and a six-month old nephew he has never met. The families have left the door open should Stockard reach a point that he doesn't feel he can make it to Florida.

"Even if he gets to a point and quits, he's already done more than most people," Jean said.

But Stockard refuses to back down from the challenge. Until the day the trip began, he hadn't ridden more than 90 miles in one day. Now he averages over 100 miles. The family rests at convenient intervals and should his legs grow weary, Dave is there to rub them down.

The Arredondos and the Borders take care of Stockard and he takes care of them. As

Stockard stands up in front of the couch he has sat on for nearly 2 hours, he turns to rouse Racheal from her slumber. Stockard waves Dave off as he moves toward the girl.

Instead of waking her, Stockard bends down near the floor and slips his left arm under Racheal's stomach. His face looks straight ahead as he scoops the child up over his shoulder and rises from the floor, turning toward the elevator.

Dave throws the styrofoam cup in the trash and tells Stockard, "Hang on a second. I'll show you where we're going." But on this trip, Stockard is the one giving the directions. It is his dream and he is fiercely determined to make it to Florida.

The Arredondos and Borders have willingly accepted their roles in the dream and will do anything to see him succeed. After all, isn't that what you do for your child?

Dave said, "We're going do it his way because this is his dream."

PINES DEAF-BLIND WOMAN IS ANTICIPATING THE FUTURE

By Lori Sykes

(Reprinted from the Pembroke Pines Sun-Sentinel, South Florida)

Pembroke Pines resident, Catalina Acevedo, 20, spent her summer months, like many other high school graduates, awaiting an acceptance letter from her chosen school of higher education.

"We are currently on a school's waiting list," Maria Theresa Escobar, Catalina's mother said. "Its going to be hard with her away at school in New York. It's so far away."

Like other kids her age, Catalina plans on learning how to be independent by going away to school. But unlike her peers, she won't be learning only what life is like away from home and everything is familiar, she will be learning how to take care of herself as a deaf-blind woman.

She wants to learn every possible means of communication, Maria Theresa said, translating for Catalina through fingerspelling. "She wants to learn how to read lips by touch so she can talk to everyone."

For the past three years, Catalina attended the Florida School of the Deaf and Blind in St. Augustine. Typically, a student is either enrolled in the deaf or blind courses, but Catalina took classes in both. She graduated this past May, third in her blind class. Charlie Krozier, the school's assistant principal, said Catalina was a very dedicated student. "She soaked up everything she could learn. She'd attend classes all day and would hit the books at night. I wonder where she could've gone if she had started here five or six years earlier. Someday she might even graduate from college."

Catalina is currently attending the Helen Keller National Center in New York. The Center is for people who are deaf-blind and teaches students how to be independent through everyday skills including how to take public transportation and how to order and pay a bill at a restaurant.

After attending Helen Keller for a year, Catalina plans on using $8,000 in scholarship money she received after graduating from St. Augustine to attend Gallaudet University in Washington D. C., a university for people who are deaf.

"All the victories and accomplishments - it seems like a dream," her mother said. "She's passed so many obstacles and learned so much."

Catalina was born and raised in Columbia, South America, where she learned braille. About six years ago, Catalina's mother decided to move her family to the United States so that Catalina could further her education. After arriving in the United States in 1994, Maria Theresa brought her children here one by one. First Catalina in 1995, then her brother Helmer, 17, and then her sister, Angelica Maria, 21.

Today, Maria Theresa has remarried. Her husband, Maurice Escobar, is also from Columbia and extremely proud of the accomplishments of his family. The rest of the family also seems to have adjusted to life in another country. Helmer attends Flanagan High School and Angelica is busy working, raising her three year old daughter, Valentina, and attending Broward Community College.

Maria Theresa communicates with her daughter, but claims she needs practice. "With her away at school I don't have anyone to practice with," she said. "We plan on going to a national seminar in Utah to learn American Sign Language and other means of communicating with Catalina."

Catalina can still see blurs, but her sight is slowly diminishing as time goes by and she can no longer make out colors.

"Catalina wasn't born deaf and blind, so she can speak some Spanish." her mother said. "When she was 5, I started to notice that she was bumping into things when she walked. Then when she was 6, she started to have painful ear aches that the doctor's couldn't diagnose."

Maurice Escobar explained "It was very tragic for my wife to find out she had a deaf-blind daughter. The doctors told her to prepare Catalina. They didn't know when she was going to come to the point when she would be completely blind."

Lauri Triulzi, a specialist with Florida Outreach Project for Children and Young Adults who are deaf-blind at the University of Florida, said that its not uncommon for a deaf-blind person to live a full life. "They can go to the store, prepare food and lead rich social lives." she said. "It depends on the person and their motivational skills. It also helps to have a lot of family and friends to offer support."

With the prospects of attending college in a year, Catalina is faced with deciding on a career. Triulzi said Catalina's employment opportunities are not limited. "I know a women who is deaf-blind. She's a pharmacy technician at the Hillsboro Veteran's Hospital," she said. "Jobs are wide open, it really depends on the person's training."

Unfortunately, Catalina won't be spending much time at all the cool hangouts with her friends. Still to shy to be in public by herself, she will be spending vacation time reading her favorite books, talking with her mother about her dreams for the future, playing with her niece, and exercising.

"Catalina has accomplished a lot since she's been here in the United States," Triulzi said. "Every person labeled deaf-blind, is also labeled unique."

EQUAL-OPPORTUNITY FOR DEFENSE

By Eileen Dempsey

(Reprinted from The Columbus Dispatch, Columbus, Ohio)

The silent darkness that envelopes Hillary Bates offers no cloak of comfort. Born deaf and with limited vision, Bates, 25, lost what little sight she had 11 years ago. Nevertheless, she has dedicated herself to learning how to live independently.

After graduating from the Indiana School for the Blind, she attended the Helen Keller National Center in New York. She learned skills that allowed her to live with a roommate in an apartment near her mother, Anne Sexton, in Crawfordsville, IN, about 215 miles west of Columbus.

Still, Bates longs for more freedom and less fear. She worries that an attacker might find her an easy target. "I usually feel a little frightened that people might become mean and try to hurt me," Bates said through her mother, who is her interpreter.

That's why she participated in a self-defense class for the sight and hearing impaired during the American Association for the Deaf-Blind's national conference at Ohio State University (OSU) last August.

"I want to feel safer," Bates said, communicating by moving her fingers quickly in her mother's hands. The two use tactile sign language because Bates cannot see traditional sign language. Although Bates is legally blind, she wears glasses to protect her eyes.

"I haven't been attacked," Bates said. "I have only had problems with two or three people who were just rude and selfish, but nobody attacked me. So, are there any techniques for rude people?"

Maybe she could try a kick, punch or block, just a few of the basic martial arts moves Tokey Hill taught during the hour long self-defense class. Hill, born and raised in Chillicothe, OH, is a former six-time U.S. national karate champion who now coaches the U.S. Karate team. While growing up, Hill, a 1976 graduate of Chillicothe High School, often competed in karate tournaments in Columbus. He graduated from Ohio University in Athens in 1983 with an associates' degree in security and safety.

In the mid-1980's, he started teaching basic moves to disabled children through a program at a New York hospital. "Martial arts develops self-esteem," Hill said. "It's a form of 'I can do it, I can do it' in an area where they have always been told they can't do it. As their skills increase, so does their confidence level."

In 1998, he started working with the Helen Keller National Center and developed a pilot program to teach martial arts to people who are deaf-blind. Such training offers many benefits, including improved cardiovascular endurance, flexibility and balance. While developing the program, Hill practiced the moves blindfolded with earplugs.

When he started teaching, Hill said he was appalled to learn about participants who had been attacked, robbed or raped. "Sometimes it's very difficult to get people to open up because they have been held back for such a large portion of their life," Hill said. "Some have always been told they can't do it. Karate is not hard at all."

Often, however, the deaf-blind have problems with balance, he said. "Martial arts is great for improving motor skills, but getting them to take that first step is key," Hill said. "Once they see they can do it, then the sky is the limit."

The self-defense techniques incorporate basic punches, kicks and blocks. "This is for real - it's not play. It is serious and it does work. You can break bones so don't do it too hard," Hill warned the class.

During the class, Bates, her mother and a friend and former tutor, Ellen Richter of Logansport, IN, learned how to twist out of a choke hold and drive a punch into the center of an attacker's chest. They were among about 50 people who crowded into the lobby of Taylor Tower at OSU for the free demonstrations. Hill presented a half-dozen sessions during the week-long conference. About half of the participants were delegates at the conference, while the rest were interpreters who explained Hill's actions.

Jessica Greenfield from Bexley also interpreted for the class as Hill and Bob Kramer, head instructor of Tigers Den Karate in Reynoldsburg, started with a series of stretches. Greenfield, a senior at Boston University, is a deaf studies major who volunteered as a support service provider at the conference to interpret.

Standing with their hands on their hips, participants rolled their heads back and forth, then moved onto shoulder, arm, chest and leg stretches. "If you feel any type of pain or discomfort, be sure you stop," Hill said. "The keys to flexibility are relaxation and breathing."

Hill told the class to breathe out when exerting energy or stretching, and encouraged participants to hold each stretch for 10-20 seconds. Hill asked participants to sit on the floor and spread their legs for one stretch.

Bates sat down in front of her mother, waiting for directions to lean forward to stretch. "I want to go farther, but I can't because she's in my way," Sexton joked about her daughter as they bent forward together.

After the class, Bates said she had learned a valuable lesson: "I can release someone if they grab my neck or shirt. I can force them away. It's a little hard, but I tried to do my best."

THIS WOMAN DOESN'T LACK THE VISION TO CREATE

(Reprinted from The Columbus Dispatch, Columbus, OH)

Hillary Bates always wanted to be self-employed. As a deaf-blind person, she felt uncomfortable taking public transportation to work.

In April, Bates and her mother, Anne Sexton, launched "My Mind's Eyes" to produce note cards featuring images made by using the embossed dots of braille.

Braille is a system of tactile reading and writing that uses characters formed by combinations of six embossed dots arranged in a braille cell. Bates uses specialized technology, including computer, embosser and software, to create the cards. Bates works from her apartment in Crawfordsville, IN, producing, packaging and mailing the cards. Her mother designed the intricate braille images of apples, teddy bears, shamrocks, flowers and monograms.

Sexton designed a catalog that showcases the cards and includes a brief history of her daughter, who was born eight weeks early with a cleft lip and palate and profound deafness. Bates lost her limited sight at age 14 and underwent three unsuccessful surgeries to regain her sight.

"We were not given the opportunity to celebrate regained sight. But in the process of acceptance and understanding of her loss, we have achieved the realization that although the majority of people have sight - few have been given the gift of vision," Sexton wrote in the catalog.

"Hillary knows that the gift of vision is hers forever: 'I am still dreaming that I am able to see, and realize I can in 'My Mind's Eyes.'"

The cards are priced from $3.95 (set of eight cards, envelopes and coordinating seals) to $6.95 (boxed set of 10 Christmas cards). For more information or to order a catalog with a sample card, you can e-mail to mme@tds.net or write to "My Mind's Eyes," P.O. Box 42, Crawfordsville, IN 47993.

WHEN DREAMS COME TRUE

By Stephanie Mitchum

(Reprinted from The Telegram, Rocky Mount, NC)

Troy Littlejohn touches those around him. Beginning with the hands of the person he encounters, he feels for rings, watches and other tactile cues. He might reach up and feel the person's head or face. Then he'll want to smell the person's hair, but that, of course, is up to the person.

The 35-year old man is deaf-blind and mentally disabled, the result of a case of German measles his mother contracted when she was pregnant with him. However, that doesn't keep him from living out his dreams.

In 1990, the NC Division of Services for the Blind discovered Littlejohn at the Murdoch Center, a state mental retardation institution in Butner where he lived from 1972 to 1995, after his mother began asking state workers for assistance in transferring him home.

Starting in 1996, officials at Murdoch and the Helen Keller National Center worked with Littlejohn's mother to create a "dream map", a plan that plotted his future. The map displays some of his likes and dislikes, his history and what officials said he communicated to them about his goals. Resembling a child's treasure map, it also reflects Littlejohn's keen awareness of both his environment and the people he loves.

Dashed lines lead to drawing of a house, symbolizing his desire to live independently of institutions such as Murdock. "Maybe alternative home with children," are printed. He wants to have children in his life. Pictures representing things he likes and wants in his life connect to the house through the dashed lines - a pool, a swing, Pizza Hut, a mall and a job.

In 1996, he wanted all of these things. In 1999, Littlejohn was able to attend the Helen Keller National Center for a year. There he learned some of the skills he would need. In the year 2000, his dreams came true.

Littlejohn has been living with a family in Rocky Mount, Ken and Kim Carnahan, since March. He has a job at the Rocky Mount Red Lobster restaurant, rolling silver-ware in napkins each weekday morning. The Carnahans, who are expecting their first child, live less than a mile away from a Pizza Hut and near Golden East Crossing Mall. They belong to the YMCA, where Ken Carnahan takes Littlejohn swimming. The family also built a swing in their backyard for Littlejohn.

"This looks like we got in a little ‘Back to the Future’ car and saw him," said Stephanie Johnson, an advocate for Littlejohn and a deaf-blind specialist for the N. C. Division of Services for the Deaf and the Hard of Hearing in Wilson.

If you saw the Carnahans out at the mall you might think they were a strange family - a young husband accompanied by his pregnant wife and Littlejohn.

The family is not surprised at what Littlejohn might do. "When he first came to our house, he bumped a picture in his room and then he just picked it up and went back to what he was doing", Ken said. "We were like, wow - never underestimate this guy." The two men have become close. "I’ve gotten so that, if I walk out of the house and he’s not on my arm, I look around," said Carnahan.

Littlejohn is happy to sit in a leather recliner and shake his head back and forth. Periodically, he will swing his arms out to his sides to see if Ken is still sitting next to him.

But Littlejohn doesn't have an opportunity to get lazy. Ken takes him to work each morning and puts the paper tabs around the silverware that Littlejohn rolls. When Littlejohn's work speed lapses, Carnahan touches his head to remind him to focus and makes the sign for "work" in Littlejohn's hand. That is how the Carnahans communicate with Littlejohn, who knows 63 tactile signs.

When he's finished rolling the silverware, Littlejohn gets his great reward - sweet tea. Sometimes, when he thinks he's finished, but isn't, he makes the sign for sweet tea, asking for it. No, Ken signs back. Work.

"When I first heard about Troy, I was knocked out", said Sheila Rowland, general manager at Red Lobster. "I'm thinking, this isn't going to work, but I've been very pleasantly pleased with how it's turned out."

Littlejohn works hard. He comes to work

every day. "I wish we had more workers like that," Rowland said.

Having Littlejohn around has changed the way the Carnahans live. Ken is the former director of a respite facility in Rocky Mount. Kim works as a case manager for the Edgecombe-Nash Mental Health. Ken wanted a change that would allow him to stay home and watch the baby. Being an alternative family living provider pays him a salary which means he can afford to stay home. "It's changed how I have to do everything," Carnahan said. "Everything takes about three times longer."

Having Littlejohn in their family has been a joy. They plan to have him as long as things work out. "It's a good match and that doesn't always happen," Johnson said.

Littlejohn has come a long way since he lived at Murdoch. What he needed was for some people to listen to his dreams. He was capable of making them come true.

"When Troy's new team came together and they revisited his dream map, it literally blew me away," she said. "This is fabulous, and Troy did it all."

HERE AND THERE

TO LOVE THIS LIFE: QUOTATIONS BY HELEN KELLER has recently been published by the American Foundation for the Blind. The book contains a foreword by former president, Jimmy Carter, and a preface by Keller Johnson-Thompson, Helen's great grandniece. The book costs $21.95 in print or cassette. It can be ordered by calling 1-800-232-3044, or by writing to AFB Press, P.O. Box 1020, Sewickley, PA 15143-1020.

Braille Group of Buffalo, New York, recently received a grant from the Josephine Goodyear Foundation to provide diabetes publications in braille. For more information, contact Jill Pariso, Diabetes Braille Project, Braille Group of Buffalo, 4660 Sheridan Drive, Buffalo, NY 14221.

Southwestern Bell Telephone (SWBT) customers can now request their monthly bills in braille or large print at no extra charge. Customers who request that SWBT provide bills in braille or large print will receive their regular bills along with the format they request. To request either format, call SWBT at 1-800-585-7928.

The new 2000-2001 No-Frills, Just Priced Right Catalogue is now available. Call Jett Enterprises at 1-800-275-5553 between 9:00 a.m. and 5:00 p.m., Pacific time to get your new copy. The catalogue is available on cassette tape or 3.5 inch computer disk, or you can visit the website at www.jettenterprises.com. The catalogue contains products for blind and visually-impaired consumers including kitchenware, jewelry, electronics, better health products, etc. Free gift tags and instructions for product use are available on tape cassette.

A new notetaker, the BrailleNote, was recently released by Pulse Data and HumanWare for immediate sale. The BrailleNote operates on the Microsoft CE operating system and includes an 18-cell or 32-cell braille display. It includes a POP3 e-mail package and internal modem. For further information concerning details about the device and for ordering, contact HumanWare at 1-800-722-3393 or visit their website at www.braillenote.com.

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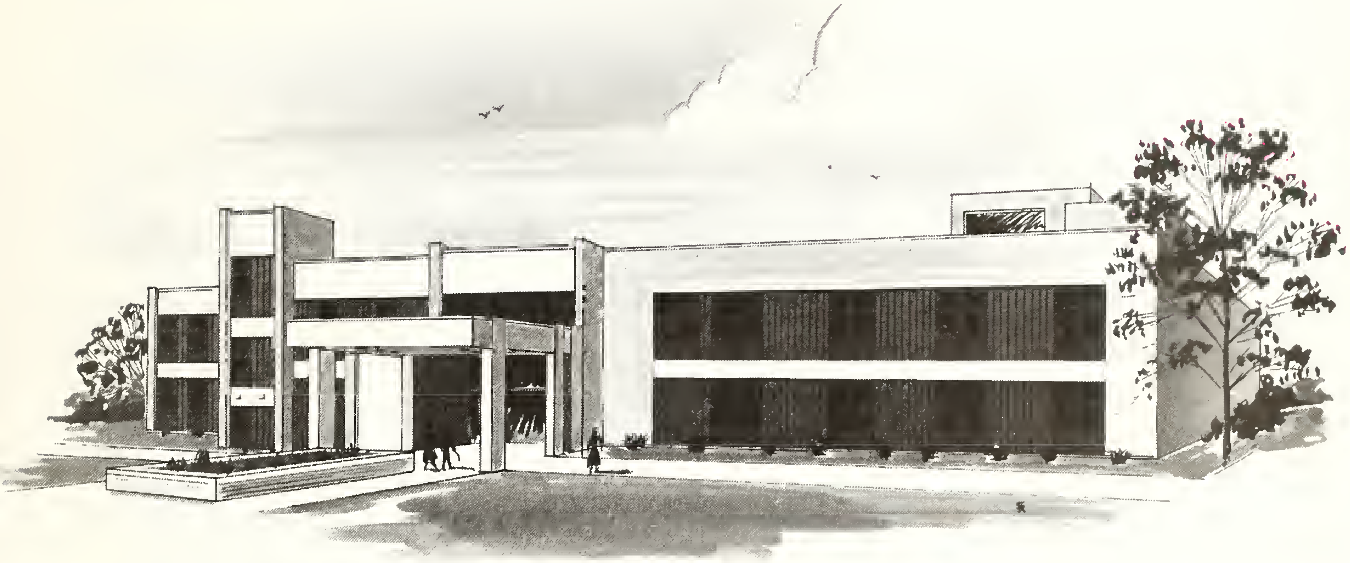

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EDITORIAL: REMEMBERING

By Robert J. Smithdas, LHD, Litt.D, LHD

In this current issue of NAT-CENT NEWS, readers will find an article describing the unusual accomplishments of Scott Stoffel, a deaf-blind student at Temple University in Philadelphia, who recently graduated with a degree in Electrical and Computer Engineering. Scott has additional physical disabilities along with his deafness and blindness and his achievements are outstanding. His example of facing difficult personal problems and overcoming obstacles should remind us of the remarkable resilience of the human spirit in testing its strength and ingenuity against the uncertain realities of life that often challenge us.

Over the years, I have had the privilege of meeting and knowing many deaf-blind people who quietly demonstrated exceptional qualities of skill and determination to succeed.

There was Ralph Carter who worked for many years at International Business Machines. On the first day of his employment, New York City had one of its worst winter snowstorms, but Ralph was determined to get to his job. He waited at a downtown Brooklyn subway station in a foot of new-fallen snow, blowing a whistle until a police car stopped and offered him assistance. He insisted on going to his place of work but, when he reached the factory, he discovered he was the only worker there.

When he retired after more than twenty years of employment, Ralph used his considerable savings to move back to Georgia where he bought land, built a house, and renewed old friendships in his original home community.

Rick Joy, who lives in California, has worked as an electronics technician for Hewlett-Packard for many years. Deaf-blind since early childhood, Rick purchased his own home in Santa Rosa, California, where he does his own maintenance, bakes his own bread, and cans his own fruits and vegetables.

Another outstanding deaf-blind person is John Boyer of Madison, Wisconsin, who owns his own small business, Computers to Help People. John is a mathematics whiz who has taken several university courses toward a doctoral degree.

These are only a few of many deaf-blind individuals I have known who have molded their lives with imagination and initiative to achieve personal success. A complete list would be a litany of challenges overcome. Being without sight and hearing is not so bad if you don't lose your courage!

WORDS FELT LARGE

By Martha Woodall

(Reprinted from The Inquirer, Philadelphia, PA, April 2001)

Scott Stoffel, who is majoring in electrical and computer engineering at Temple University, had no trouble coming up with a topic for his required senior design project. He was studying engineering because he wanted to learn how to develop a small electronic communication device to help blind and deaf people who have trouble deciphering the tiny raised dots of Braille with their fingers - people like him!

So Stoffel, 32, who is legally blind and deaf, invented what he calls a computer-automated palm Braille system to expand the communication options for the estimated 100,000 people in the United States who are deaf and blind. He said he believed that his instrument could be produced at a fraction of the cost of larger electronic Braille devices.

Although Stoffel has plans for a wireless version that could work with personal digital assistants such as Palms, his instrument now connects to the parallel port of a PC or laptop using a standard cable. The "palm" in the name of his invention refers to the part of the hand that users rest on the tool to feel the six large pins that are raised and lowered to represent the combination of dots that create individual Braille letters.

A prototype is being completed. The Helen Keller National Center plans to test the device with its students this summer. Stoffel is dreaming of improvements for the next version in hopes of selling the concept to a company that makes Braille devices.

"Communication is probably the single most important thing there is to a human being, aside from the basic necessities," Stoffel wrote in his senior project proposal. "We use our eyes and ears to absorb text and speech. But how would someone get along in the information-driven world of today if he/she could not see or hear effectively?"

Those who know him say Stoffel is the epitome of determination and grit. Reading is a laborious chore for him, yet he maintains a 3.7 grade-point average in a demanding major. He has written a fantasy novel, "The Last Days of Magic," which is scheduled to be published by Domhan Books in New York this spring, and he is a finalist to be a speaker at Temple's commencement.

"I can honestly say that he has changed my outlook on life," John J. Helferty, chairman of the Electrical and Computer Engineering Department, wrote in nominating Stoffel to be a student commencement speaker. "His sense of humor in the face of monumental challenges and difficulties is something I will never forget."

Stoffel said he had been thinking about

creating a communication device for years. "I had the original idea around 1996 when I was working at the Helen Keller National Center in New York," Stoffel explained in an interview conducted at Temple's Ambler campus with Helferty's aid. The professor typed questions on the computer for Stoffel to read in a large font.

"I was talking to a colleague in the Technology Department at the Center about the idea of a sort of 'large-print Braille' for people like me who have sensitivity problems and can't read regular Braille or for people who can't move their hands back and forth," Stoffel said. "How about a stationary kind of monitor that just scrolls in place so a person doesn't have to move?"

Stoffel has a degenerative neurological disorder. Although legally blind since the age of 4, he has some sight and can read large, boldface letters up close. His hearing deteriorated suddenly when he was 19. His disorder also causes a numbness in his fingers that makes it difficult for him to read Braille with his fingertips. The dots are too small and too close together for him to distinguish the patterns.

He has completed his classes at Temple by slowly reading text using a large font on his computer screen, and by E-mailing his professors and meeting with them individually. Sometimes interpreters attend classes with him to translate professors' remarks using tactile sign language, in which they press the signs against his hand.

Stoffel lives in an apartment in North Wales, Montgomery County, with his wife, Sandra, who is also deaf and visually impaired. He already had taken some computer and writing courses at Hofstra University in Hempstead, NY, when he enrolled at Temple two years ago.

During a meeting with the Engineering Department representatives, Stoffel explained how he accessed information. "I asked them: 'Seriously, do you guys think I possibly could do engineering? I don't want to waste my time. This is not something I am doing just for the sake of getting a degree. I want it to be a practical career for me.'"

Helferty encouraged him to take advantage of Temple's new computer engineering option in the Electrical Engineering Department. "He can't physically go into a lab and wire things up," Helferty said. "But with most of your design at the engineering level, technicians go in and wire things up. All the design is done using computer-aided-design software."

Helferty helped Stoffel construct a mock-up and then build the prototype of his computer-automated Braille system. But it was Stoffel who wrote the software program that reads and writes Braille, and designed the hardware.

When a floppy disk with his Braille

program is inserted into a computer, it moves the six pins in the proper sequence to create individual Braille letters. The pins are push-type tubular solenoids.

In its reading mode, the program converts ASCII text files into Braille. The term - which is pronounced "ASK-ee" - stands for American Standard Code for Information Interchange. Most books, including textbooks, are available in ASCII file format for DOS on disks. Although Stoffel plans to create a Windows version, he elected to start with DOS because many blind people have older, donated computers that rely on DOS. Plus, newer Windows machines can use DOS, too.

The software that Stoffel developed also displays Braille in a large format on the computer screen for those with some sight. Users can change the colors of the background and the dots. They also can control the speed of the device and the force exerted by the moving pins.

"It is very versatile," Stoffel said as he demonstrated the system. "It has 64 different colors. You just use the shift key and a letter to change it instantly."

The materials for the hardware cost him $213.67, and he said he believed that his system could be sold for less than $1,000.00 - including labor. Electronic Braille readers that attach to a PC for use by those who are able to read traditional Braille can cost $10,000.

James Belanich, adaptive technology coordinator at the Helen Keller National Center, said existing electronic Braille readers were very expensive because they have rows for as many as 80 small Braille characters. Stoffel's device handles one large letter at a time. Belanich said no similar product had been developed before because the market was so small. "One great thing about this device is it gives an option to someone who has no other options," he said.

Stoffel recalled that while he was working as an instructor at the Center, he was in contact with a young deaf-blind woman in Kentucky with cerebral palsy. "She couldn't move her hands to read Braille," he said. "She didn't have any way to access text except through Morse code using vibratory noise. She would feel buzzes - long versus short. It was extremely slow. That is all she had."

Stoffel said that, with his device, the young woman would be able to read Braille because a strap could hold her hand in place so she could feel the moving pins spelling out the Braille letters.

Former instructors and colleagues at the Helen Keller National Center are not surprised that Stoffel has created his computer-automated Braille system and is obtaining his engineering degree. "Engineering is a brutal field," said Anne Sedewitz, now admissions coordinator at the Center, who was Stoffel's rehabilitation counselor. "But knowing him, I am not surprised that he did it. He is brilliant. And he has the determination and the motivation to succeed."

DEAF-BLIND GAIN INDEPENDENCE AT HKNC

By Todd R. Olsen

(Reprinted from the Monthly Communicator, New Jersey Department of Human Services, Division of the Deaf and Hard of Hearing)

HELEN KELLER NATIONAL CENTER
FOR DEAF - BLIND

Suppose you are deaf-blind. Where could you go to increase your vocational or independent living skills? As I found out - the answer is not that difficult to find. People who are deaf-blind and anxious to improve their quality of life, could go to the Helen Keller National Center

(HKNC).

HKNC is a 25-acre, two building training center located in Sands Point, New York. It houses about 100 staff and 40 deaf-blind students. The main goal is to educate deaf-blind individuals on how to become more self-sufficient.

HKNC provides case managers, vocational counselors, and other support staff, who provide instruction on various tasks for life. They offer a wide range of direct services.

Some of their services are as follows: the PATH Program (Person-Centered Approach Toward Habilitation) is designed to teach students through a hands-on, real life approach to skill development; case management provides program planning and coordination, vocational counseling, contact with sponsoring state rehabilitation agencies, contact with family, and transition/placement services; the Independent Living Department teaches independent daily living skills; the

Orientation and Mobility Department enables safe and effective means of travel; the Low Vision Department teaches use of residual vision more effectively; Vocational Services evaluate and assist with meeting employment goals; the Creative Arts Department provides the opportunity for self-expression through artistic means; and lastly, HKNC offers mental health services to assist individuals with their personal life situations.

Along with these services, HKNC also has a Communications Learning Center and a Technology Center.

On January 12th of this year, I visited HKNC to see first-hand how the facility and its different programs operate. I had the opportunity to meet some wonderful students and staff. I talked with them in depth about the services that were being provided. I saw most of the programs and had a guided tour by one of the students, Agatha Munn. I also met with Dora Carney, who is a case manager for HKNC.

Overall, I would have to say that HKNC is a phenomenal center for life development. I truly wish that I could attend as a student and take part in the rich experience provided at the training center. I would also highly recommend this facility for all deaf-blind individuals.

Any New Jersey deaf-blind resident wishing to attend HKNC should contact a NJ Commission for the Blind and Visually Impaired (CBVI) counsellor. Elida (Lee) Gares is the Northern Case Manager and she can be reached at (973) 648-7888 Voice or (973) 648-4599 TTY. John Walsh is the Southern Case Manager and he can be reached at (856) 614-3018 Voice or (973) 648-4559 TTY. You can also find more information about HKNC by e-mail: hkintake@aol.com; (516) 944-8900 Voice; (516) 944-8637 TTY or write: 111 Middle Neck Road, Sands Point, NY 11050

(The mission of the Helen Keller National Center for Deaf-Blind Youths and Adults is to enable each person who is deaf-blind to live and work in his or her community of choice).

ONE SUMMER, BUT A LOT MORE THAN ONE EXPERIENCE

By Scott Davert

My name is Scott Davert. I'm both completely blind and hard of hearing. I have been blind since birth and my hearing has slowly deteriorated over time. I'm now a senior at a regular public high school holding a 3.5 GPA. I take mainly college prep classes because that is the direction in which I'm headed.

In July 2000, I attended a two week seminar at the Helen Keller National Center (HKNC) for high school students. The Center is located in New York. It is the only Center in the country that specializes in training deaf-blind individuals. They offer many great programs in a wide variety of areas. They can help deaf-blind people with mobility, cooking, cleaning, and they even offer a vocational program to give future employees a chance to gain experience in the career that they think they might want to pursue.

Getting to HKNC was an adventure for me in itself. I flew there on my own. That was a new experience for me because I had never been on an airplane by myself. At that point, I had second thoughts about going. On one hand, I was excited about going, but on the other, I was real nervous because I did not know anyone there. It meant taking a step from the known into the unknown.

I arrived at New York's LaGuardia Airport alive! It was a hot and humid Sunday afternoon in July and the airport itself was a lot busier than I had expected. It seemed like it was busier than Detroit Metro Airport on the holidays. The people from HKNC were there to meet me and I was happy about that. I was kind of worried something might have gotten messed up and they might not have been there to get me.

I was quite surprised to find that HKNC was an easy place to get around. There were no streets to cross and there were only two buildings that we used, which were right across from each other. At HKNC, I had my first exposure to sign language. I also met several people who were deaf and almost completely blind. I found that they lived just as fulfilling of a life as me; if I completely lose my hearing, I could still get along in life.

I think the best thing that I got from attending the seminar at HKNC was confidence. As it stood then, and still does now, I don't need to do my own laundry or find my way to where I want to go. I knew how before, but I never had to use those skills until going to HKNC. The best part about the whole experience is that if I didn't know how to do something and I wanted to be taught it, all I had to do was ask. If the staff knew how to teach me, they did.

I also had the opportunity to visit the Statue of Liberty and to go into Manhattan. The Statue of Liberty trip was alright. Manhattan, however, was much better. The high school students, including me, went to eat at Planet Hollywood. We also went to a place called Virgin Records, which is the biggest music store I have ever visited. It is three stories of nothing but CD's, cassettes, books, and other music related materials.

When it was time to leave HKNC, I had mixed emotions about going. On one hand, I did want to go home to see my family. On the other, I wanted to continue experiencing new things, meeting new people, and living on my own.

I strongly recommend that any deaf-blind individual seeking training in any matter go to

HKNC if at all possible. I have found the two weeks I was there to be very helpful both socially and mentally. I hope to return there next summer for a lot more training before I head off to college.

Last summer, I also attended the American Association for the Deaf-Blind Conference in Columbus, Ohio. The American Association for the Deaf-Blind (AADB) puts on this conference every three years in different locations around the country. The purpose of the conference is to help deaf-blind people meet one another, as well as to educate deaf-blind people about services and technology that are now available to them. Workshops included martial arts, self-determination and they even had one for teenagers!

I had a good time. My SSP's, or support service providers, were Beth Kennedy and Bob Harkness. They basically took me wherever I wanted to go and gave me any help that I needed. I met lots of new people. I also caught up with quite a few of the people I had met at HKNC the previous week. There were many socials in the evenings and lots of workshops during the day.

The AADB Conference was not quite as frightening as going to HKNC because I had already been through a similar experience. All in all, the summer was a great one! It was filled with new experiences and new people. If I could go back and relive any summer over again, this would definitely be the one I would pick!

REFLECTIONS ON HISTORY: THE MAKING OF THE WORLD'S ONLY DEAF-BLIND LIONS CLUB

By Cynthia L. Ingraham, East Central Representative, Helen Keller National Center and Paul Richard McGann, Charter President, Pittsburgh DeafBlind Lions Club

The Pittsburgh DeafBlind Lions Club had its Charter Night on November 17, 1994, but the history of the club goes back longer than that!

Often at the start of a new year we reflect on the progress made over the course of the previous 12 months, and make plans to enhance our lives in the months ahead. The year 2000 not only signaled the ending of a decade, century and millennium; it closed the chapter on one of the most astounding periods in the history of services to persons with disabilities.

In 1880, just prior to the beginning of this past century, Helen Keller was born in a small town in Alabama. She was a very bright and energetic young child, who enjoyed sharing special moments with her father. Before she would reach the age of two she was stricken with an illness so severe it would steal her vision and hearing.

After years of struggling to communicate with family members, a light came into Helen's life. Anne Sullivan was a reluctant heroine and guiding light for Helen; and would soon pave the way for our modern day Miracle Workers. What was so remarkable about the achievements of both Helen and Teacher was that they agreed to trust one another and to be each other's support system. With the help of Anne Sullivan, Helen was able to attend and graduate from college with honors. This achievement marked the first time in history that a person without vision or hearing would successfully graduate from college.

Following her college education, Helen held numerous jobs, but the one that would have the most impact on the education of persons with disabilities would be her role as a motivational speaker. Helen toured around the country encouraging Wold War I soldiers and others who were faced with barriers of all kinds.

In 1925, she attended the International Convention of the Lions in Cedar Point, Ohio. She challenged the Lions to become "Knights of the Deaf-Blind." Many in attendance misunderstood her plea and pledged to work with persons who were deaf and persons who were blind. As a result of Helen's challenge, for many years the Lions Clubs have served as a source of financial and spiritual support for millions of people who are blind across the globe.

On November 17, 1994, Helen's dreams became reality when the Pittsburgh DeafBlind Lions Club was formed. The Club, which was originally christened the Western Pennsylvania Association of the Deaf-Blind (WPADB), was established by Richard McGann as a support group for deaf-blind consumers and others interested in working with them.

Back in the late 1980s and early 1990s, WPADB members and supporters would gather monthly at the Catholic Office for the Deaf to provide workshops and trainings for volunteers of all ages who were interested in becoming Support Service Providers (SSPs) in the community; or at the annual American Association of the Deaf-Blind conventions.

In 1987, the WPADB actually hosted the AADB Convention, raising more than $16,000 in six months for that purpose. There were 350 delegates (deaf-blind persons) and SSPs (Support Service Providers) in attendance that year. The convention was held on the campus of California State University in Pennsylvania. Many of the local SSPs trained by the WPADB helped to accommodate the housing, transportation, entertainment and communication needs of the delegates attending the convention.

The connection of the Western Pennsylvania Association of the DeafBlind with Lions Clubs International came in 1993. A deaf-blind high school student from the

Pittsburgh area wanted to attend the AADB Convention in California but did not have the money to get there. Cynthia Ingraham, original member WPADB and East Central Regional Representative for the Helen Keller National Center, petitioned the Lions Clubs for assistance.

She was referred to Anthony Cicco and the McKees Rocks Lions Club who agreed to fund the trip for the student. When the funds were delivered to Cynthia Ingraham, she was introduced to Joe Donkin (the Incoming District Governor) who, along with Mr. Cicco, was interested in organizing a new Lions chapter for the deaf (there was previously a deaf Lions Club, but it disbanded.)

After much discussion, they all decided that a deaf-blind chapter would be an even better idea. A meeting was arranged with representatives from WPADB to discuss setting up a DeafBlind Lions Club. The people from WPADB saw this as an excellent way to develop leadership skills for deaf-blind persons, promote charity work, raise funds to purchase equipment for deaf-blind people and to help get people to the AADB Conventions.

The Pittsburgh Host Club sponsored the Pittsburgh DeafBlind Lions Club. Pittsburgh Host Club member, Father Gary Patriquin, served as the Guiding Lion. When Father Gary had to step down due to illness, the task was assumed by PDG Jack Schimmel from the Bloomfield/Lawrenceville Lions Club, who continues to advise the club on matters of protocol. Lion Anthony M. Cicco and PDG Joseph Donkin received Club Extension Awards for helping to organize the club.

The club has members who are deaf-blind, deaf, blind, or mobility impaired as well as those who do not have sensory or physical disabilities. All meetings and events are accessible and interpreters are provided. The monthly newsletter is published in regular type, large print and Braille.

The Pittsburgh DeafBlind Lions Club's Mission Statement declares, "The Pittsburgh DeafBlind Lions Club is an inclusive membership organization. Founded in 1994, members strive to spread awareness and raise resources for agencies and individuals who serve or experience sensory impairments."

The club is very active in supporting general Lions activities. The Pittsburgh DeafBlind Lions Club has contributed to the WQED (Pittsburgh's local public television station) Video Captioning Program, B.O.L.D. (Blind Outdoor Leisure Development), the Blind Bowlers, Lions' Beacon Lodge Camp in Mount Union, PA, and the Guide Dog Foundation. In April of 1997, the club presented Pittsburgh Vision Services (PVS) with a check for $1900 to aid in the purchase of a new Braille embosser.

The Pittsburgh DeafBlind Lions Club also has three major goals related to deaf-blindness:

Awareness/Education Goal: To provide information to "Lions Club International" and the community regarding the needs and abilities of deaf-blind persons. To serve as a role model for future DeafBlind Lions Clubs.

Social Goal: To enhance the personal enjoyment of persons who are deaf-blind through fully accessible recreation and social interaction.

Access to Assistive Technology: To help defray the costs of access technology necessary for the independence of persons who are sensory impaired.

The Pittsburgh DeafBlind Lions Club is unique. It is currently the world's only Lions Club dedicated to serving the deaf-blind community. Yes, they are Lions, but they try to be more than that. And they hope to show that anyone, regardless of disability, can, with a little assistance, participate in helping others.

DEAF-BLIND ARTIST DEFIES EXPECTATIONS

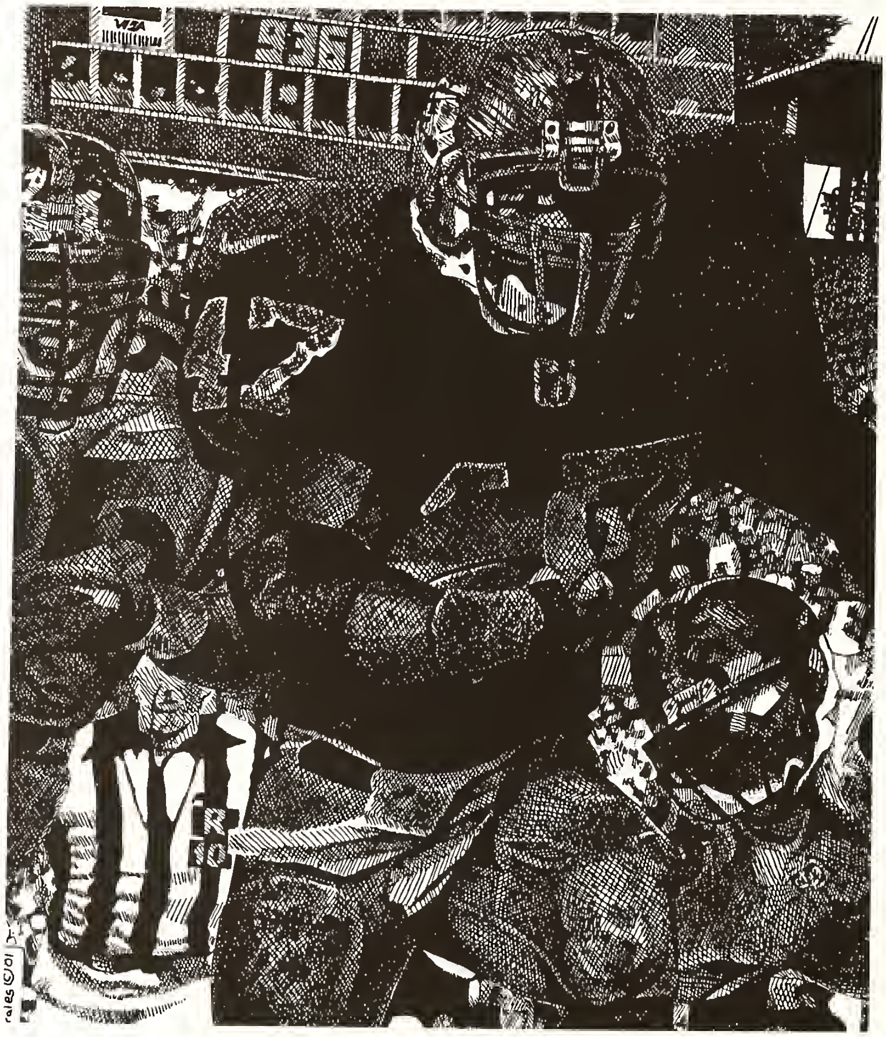
By Dennis Rockstroh

(Reprinted from the San Jose Mercury News, San Jose, CA)

One of the things I love about this business is that every once in a rare while I get to meet someone like Raphael Morales. To say that he battled great odds to achieve his dream is the understatement of understatements.

Deaf and legally blind, Morales is a published illustrator. He can see this story one square inch at a time.

For the past five years, Morales has been an art student at Ohlone College in Fremont, CA. His teachers and advisers say that he is now ready for a professional job. Already, his illustrations - mostly of sports figures - have shown up in the college newspaper, the MONITOR, and once in the Bay Area sports pages of the Alameda Newspaper Group. Pro football's Deion Sanders with pouting lips and very big head pushes out from one illustration. A mild-looking Barry Bonds of San Francisco Giants fame is about to launch the baseball, while in another picture, former Denver Broncos quarterback John Elway's head is breaking out of his helmet. Morales draws with a bit of attitude said his art professor, Dave McLaughlin.



That Morales got this far is a testament to the passion that drives him. His parents, like most parents of children with Usher syndrome, were probably baffled by the disease which robs children first of hearing, then of sight.

In high school in San Jose, Morales was told constantly to give up his attempts to draw, to create, to make a contribution, to make his mark. But he would not. A friend told him about Ohlone College and he enrolled in 1995. Under the tutelage of McLaughlin, who recognized his talent and the fire that drove him, Morales got his chance to learn and become an artist - as unlikely as that seemed.

Last year he showed up at the MONITOR counter to ask for a spot on the campus newspaper.

Graphics adviser, Gerry Mooney, asked him to come back with some samples of his work. When he came back the next day with a portfolio, Mooney's reaction was quick. "Wow, I think we can find something for you to do," he stammered. "Don't go away."

McLaughlin, Mooney and newspaper adviser, Bill Parks, have worked with Morales, helping him develop. They are trying to get him work with a professional sports team. So far, no luck, but they plan to press on. And so does Morales, despite the odds. "When he first came to us, he could see about a square foot," said McLaughlin. "Now he can see a square inch."

Usher syndrome took Morales' hearing completely at birth 28 years ago. When he was about 2, his sight started to go. Over the years, it has become progressively worse.

Morales has never spoken a word, heard a sound, yet he talks non-stop with his hands and his body - challenging his interpreter to keep up. As he told his life's story, "frustrate" was his most common verb.

Morales first learned of his talent as an artist when he was 7 and saw a film about Frankenstein with his family. "When I got home I tried to draw Frankenstein," said Morales through interpreter, Kelly Wilmeth. "I loved the movie so much. My parents saw my drawing and were shocked. They said I was pretty good."

Every time he got a chance, he grabbed pencil and paper and drew. "I struggled badly with my eyes. The school told me to stop because I wasn't going to be able to do this," he said. But Morales persisted despite his worsening tunnel vision. He learned sign language and uses it - and writing - to communicate.

Morales said that he got little support for his drawing until he got to Ohlone College. When his work was published in the MONITOR, Morales was ecstatic. "I looked at it and was so proud," he said. And, when a chain of daily newspapers recently published his work, he tried to stay cool. "I didn't want to give the appearance of arrogance, but I felt really proud," he said.

"He has a sharp wit and a sense of satire," said McLaughlin. "His work has an edge and is not always complimentary." Those who see his pictures and hear his story are awed by Morales' accomplishment. "I was stunned by the quality of his work," Mooney said. "It's just outstanding work."

But Morales, at 28, is running out of time. "He might not see much longer," McLaughlin said. "It seems to take its toll at about 30." Morales knows what is happening to him, but the passion to draw still burns brightly in him. Still, he knows he must prepare for the inevitable.

For the next four months, Morales is in New York at the Helen Keller National Center learning Braille and how to live in a silent and sightless world. The future is uncertain for this blind and deaf artist who deeply touches those who know him. But Raphael Morales has already left his mark. "He's as rare as they come," McLaughlin said.

Raphael adds: "I decided to come to the Helen Keller National Center to focus on the skills that would help me prepare for employment in the field of art. My other main focus is to improve my English skills in reading and comprehension. I also hope to learn adaptive skills in orientation and mobility and independent living. I am grateful to my VR counselors in the state of California for all the interest and support they have provided me with over the past few years. They have continued to show their support throughout my training here at HKNC."

WHEN SIGHT AND HEARING ARE A PROBLEM

by Ravon Sheets, Capital High
Charleston, West Virginia
(Reprinted from WORLD AROUND YOU, Gallaudet University)

Editor's Note: The following article, written by a young high school student who has Usher syndrome, is a straight-forward personal account of the problems she faces because of the limiting effects of her condition caused by the syndrome. The experiences she describes are perceptive and sensitive, and should provide a graphic insight into what happens when the world begins to fade.

I have Usher syndrome, a condition that causes increasing loss of hearing and vision, including night blindness and tunnel vision.

Having Usher syndrome can be frustrating. I have trouble communicating with my friends at school, especially during my lunch break when we are standing in a group talking. Most of the time, someone is caught up in telling a story about something that happened that morning and he or she forgets to face me. I cannot read his or her lips and, although a few of my friends can sign, they are too busy laughing and hanging on the speaker's words. They forget that I can't understand what is being said. It makes me feel really alone - like someone looking through a window at everyone on the other side.

Afterwards, a friend will try to sign to me what was said and it makes me feel a lot better. Still, it isn't the same as hearing it from the speaker and being able to laugh along with everyone else. Also when I go to after-school football games, I can't see in the dark. I can't wander around with my friends and they don't understand.

Usher syndrome is frustrating not only for me but also for my friends and teachers as well. My friends and teachers will try to tell me something but sometimes I don't understand. When I ask them to repeat, they get angry. They reply "never mind," or "don't worry about it."

Even worse, sometimes they repeat it in slow, open-mouthed phrases that make it even harder to understand. I get really angry when people do that to me, but I try to understand what it would be like to be in their place. Teachers usually have more patience than people my own age.

Almost two years ago, I underwent an operation to have a cochlear implant, which is a device that is implanted in a space where a piece of skull has been removed behind the ear and a wire is extended into parts of the ear to create artificial sound. I am hoping that with time and dedication, I will be able to use my cochlear implant to communicate better with people in the hearing world.

GETTING TO KNOW AGATHA MUNN

Interviewed by Todd R. Olsen

(Reprinted from the Monthly Communicator, New Jersey Department of Human Services, Division of the Deaf and Hard of Hearing)

Agatha Munn is a deaf-blind resident of New Jersey who is currently enrolled at the Helen Keller National Center. She has been married to Kevin Munn for 28 years and has a daughter named Lisa.

Question: Can you explain a little about the cause of your deaf-blindness?

Answer: Well, I have Usher syndrome Type I. It combines congenital deafness, retinitis pigmentosa and a balance problem. There are other types of Usher syndromes that

I will try to briefly explain.

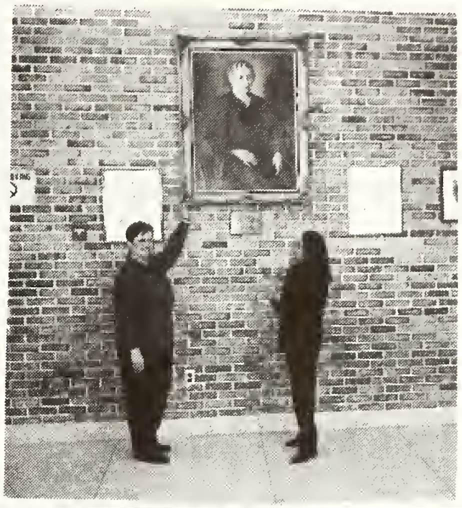
Usher syndrome Type II, is a combination of retinitis pigmentosa and hearing loss, but unlike Type I, there is no balance problem. Usually, individuals who have Type II have enough vision to lip-read and some can even talk on voice phones.

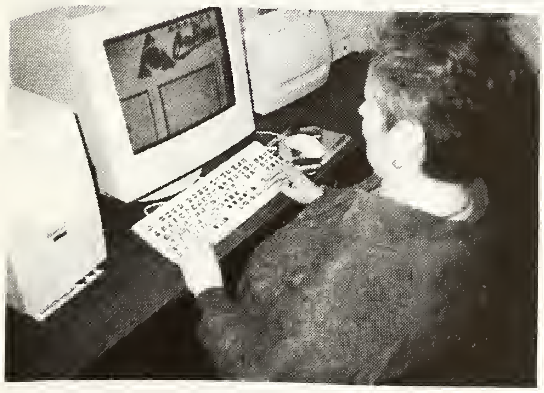
The last kind, Usher syndrome Type III, is when a person is born with hearing and vision, but as they grow up, they develop retinitis pigmentosa and experience hearing loss. As with Type II, Type III individuals usually have good balance, have some useful vision and may use voice phones.

I encourage anyone who is interested in this area to contact the NJ Library for the Blind and Handicapped at (800) 792-8322 Voice or (877) 882-5593 TTY for more information.

Question: How has the Helen Keller National Center benefitted you so far?

Answer: I would first like to say that all the staff at HKNC have been a tremendous resource. My counselor is Dora Carney and I thank her very much for her support.





Top: Agatha and Dora Carney.

Bottom left: Agatha and Lauren Wendelken, Sr. Instructor in the Independent Living Department

Bottom Right: Agatha and James Feldman, Instructor in the Technology Center.

I have been attending classes on: Braille, general computer orientation, Microsoft 2000, AOL, mobility and orientation, cooking and more. They have greatly increased my skills for independent living and working. As much as I have learned, I still have some areas that I need to focus on. Luckily, I will stay here until all the goals have been completed. I have been working very hard and look forward to achieving everything that has been set out for me.

Question: Has HKNC changed your life?

Answer: Absolutely. HKNC has changed my life wonderfully. I have made new friends and now think more positively. There is currently better understanding of people who are deaf-blind. It is not like decades ago when deaf-sighted students made fun of the deaf-blind students. There was a lot of anger and emotional problems in the School for the Deaf. The deaf-blind students felt isolated from the world. But now at HKNC, I feel welcomed and more accepted.

Question: What is the most difficult

adjustment about being at HKNC?

Answer: Leaving my family is most difficult. I miss seeing them and being at my own house. I frequently chat with Kevin and Lisa through e-mail friends, my brother Albert, my sister Patricia, and Kevin's family and friends. Once in a while I call my 80-year old father, stepmother Dottie, oldest sister Stella, my father-in-law, and other relatives via the relay center.

Question: I know that you have been learning a lot at the Center, but can you mention just one of your accomplishments there?

Answer: That is true. I have been learning a lot and it is difficult to mention one achievement. I guess one of the most important items that I learned is orientation and mobility. That program has trained me on how to use a mobility cane. I have never used one before, but now I currently use a mobility cane for many activities. This aids in my independence by not having to rely on family or friends to guide me. I live at the Center during the week, but on the weekend, I take the trains home by myself. I take the NJ Transit from Metro Park to Penn Station in New York City. I then get off at Penn Station and transfer to the Long Island Railroad. The LIRR takes me to Port Washington. There, I get off and take a cab for about five minutes to Sands Point.

Question: What kinds of activities are you involved in at HKNC?

Answer: I joined the Town Hall Committee. There is a meeting every Tuesday afternoon. We encourage solutions to problems that may arise at HKNC. An example of what the committee might face include problems in the cafeteria, or computers for the Residence Hall, or the encouragement for the community to use Braille. The committee recently suggested fund raising to get a new Braille computer.

We will need to raise $10,000 to buy the computer.

Question: Lastly, would you recommend HKNC to other deaf-blind individuals.

Answer: I definitely would recommend HKNC to all deaf-blind people. There is so much to learn here that I couldn't possibly explain it all in this interview. I suggest that people contact the Center for information.

Left: Dora Carney and Agatha admire portrait of Helen Keller in the HKNC Lobby.

Right: Agatha demonstrates her computer skills.

COMMUNICATION TERMS AND NOTES

by Theresa Smith

Guidelines: Working and Socializing with Deaf-Blind People

Major causes of deaf-blindness: Usher's syndrome, maternal rubella, combinations of deafness with conditions causing blindness (e.g. deafness and optic atrophy, deafness and glaucoma).

Usher Syndrome

Usher syndrome is a hereditary condition resulting from an autosomal recessive gene. It results in the combination of congenital nerve deafness and blindness from retinitis pigmentosa (see below.)

There is no cure and no treatment. There is considerable research being done on both seeking a treatment or cure, and on identifying the genes which carry Usher. There are several types of Usher. The two most clearly identified and the two most commonly mentioned are: Usher Type I (congenital profound deafness with RP) and Usher Type II (partial hearing loss with RP).

They are caused by different genes, both of which are recessive. Other types of Usher are not as clearly defined and are quite rare. As many as six were tentatively identified, but further research muddied rather than clarified these distinctions. It seems there are many different kinds of eye conditions that resemble or appear to be retinitis pigementosa and doctors do not yet clearly understand all the differences.

For interpreters the most significant difference between Usher I and Usher II is the language base. People with Usher Type I are more likely to use ASL while people with Usher Type II usually have English as their first language and sign in a more English-like way. Some people called Usher II are born and remain hard of hearing. Others, also called "Usher II" are born with normal hearing which they gradually lose, eventually becoming deaf.

The implications for style of signing are the same, that is the interpreter should sign in a small space in front of himself, near his face, if the person still reads signs visually, or sign tactually if the deaf-blind person vision has reached that point.

Retinitis Pigmentosa (RP)

A hereditary disease causing progressive blindness. Early symptoms include tunnel vision and night blindness. Gradually the tunnel fills in, becoming smaller and smaller until the person about the age of forty to fifty is essentially totally blind.

Leslie Petersen, who has Usher Type I, said he "went blind" four times. It was a succession of major losses caused by progressively more loss of vision. The first was losing the ability to drive. Although he could still see in a small area, it was not safe for driving. The second loss was the loss of reading signs visually. His field (range of vision, or the area covered by the tunnel of clear vision) had become too small to see enough of the signing space to read signs visually. He had to begin to use touch to communicate. The third was losing the ability to read regular print. This much vision was restored by a cataract operation, but eventually the RP made it impossible again, the fourth time he "went blind."

The age at which each loss occurs varies somewhat from person to person. People with Usher Type II seem to lose their vision slower than those with Usher Type I. In general, night blindness occurs very early, as early as six to eight years old. Driving and being able to follow group conversations in sign are a problem in the person's late 20's and early 30's, and within ten years reading regular print is difficult. A black, felt-tip pen and clear penmanship are usually adequate for another ten years. Meanwhile, the tunnel of good vision gets smaller and smaller. Some time in a person's thirties they need to touch to understand Sign, moving from tracking to tactual communication.

Tunnel Vision.

Although this is more a lay than a technical term, it is well to remember that the size of the "tunnel" varies considerably from person to person, from day to day and from room (lighting conditions) to room. Secondly, it is not strictly a tunnel. It is more like an irregular doughnut or tire-shaped area of blindness. This means the person with tunnel vision has clear vision in the center (like looking down a roughly made tunnel) but still has some little blurry vision on the extreme periphery. If you stand at an angle to the side and wave, they will not see you, but if you come from behind and walk past their side, they will notice.

Patrick Cave, a deaf-blind man with Usher describes the early stages of tunnel vision as being like looking through a camera lens and trying to get everyone in the group "in the picture." You keep asking people to get closer together, and you keep standing further and further back.

The "tunnel" is usually less than ten degrees before a person begins to identify themselves to others as having tunnel vision. A 35mm camera (often actually 50mm) takes in about 50 degrees (depending on the focal length). A normal field is 180 degrees, so this is after most of their friends have already noticed that they appear clumsy, that it is hard to get their attention and that they often miss things. Ten degrees is not very much vision; twenty degrees is legally blind.

Most deaf-blind people with tunnel vision can read signs visually without a problem when the overhead lighting is good, and when the background behind the signer and clothing of the signer are dark and non-reflective. The smaller the tunnel (as the blindness progresses) the harder it is for the deaf-blind person to see enough of the signs to understand. To get a sense of this, try looking through a tube of some kind (e.g. an empty toilet paper roll). You will notice that just like the camera lens, the further away a person is, the more of them you can see.

Remember too that this "tunnel" is also irregular, that is it does not form a symmetrical or round tunnel. It may be somewhat squashed. There may be small islands of blindness within the area of good vision. Typically there is also a tiny, halo-like ring of remaining, useful vision on the far periphery of the person's vision. This is useful for noticing movement or large white objects on the periphery. The deaf-blind person might miss steps but notice a piece of paper on the ground as they step over it.

In meetings, people with tunnel vision are usually able to read the signs of a platform interpreter (assuming background, etc., are appropriate) but are not able to look back and forth from the stage to a speaker in the audience. The deaf-blind person might not even be able to look back and forth between the speaker and a platform interpreter quickly enough to avoid missing information.

Thus, a platform interpreter for people with tunnel vision would appropriately:

a) identify who is speaking (e.g. questions from the audience)
b) include visual information such as how many people have their hands raised, audience reaction, significant movement/changes on stage, etc.
c) copy sign what others are saying even when they are in the front of the room (e.g. also on the platform)
d) include visual print information that is

difficult for visually impaired people to read e.g., information on overhead projectors.

"Tunnel Vision" is also an identity, that is, a person who has only a tiny tunnel of good (or better) vision, for example with which to read print may still identify her/himself as having "tunnel vision", rather than being "deaf-blind" even though he must use his hands to read signs.

Night Blindness

"Night blindness" is really difficult seeing in dim or poor light conditions (that is, it is about the light, not the time of day). Dim lighting also occurs in some stairwells, hallways or in some restaurants. Deaf people with night blindness would have difficulty seeing well enough to read signs but they would also have difficulty walking down steps or on rough terrain when the lighting is bad. Their reduced vision coupled with bad balance make it very difficult in such circumstances. Several kinds of eye diseases cause night blindness, but it is particularly marked in RP.

Cataracts

A fogging of the cornea of the lens which causes problems with acuity and glare. It is operable. The impaired lens is replaced by an artificial one, either in glasses, or an implanted lens within the eye.

Looking through a dirty window is very similar to what cataracts look like. When the sun is on the window, it is almost impossible to see through, but when it is in shade, the dirt is harder to see - less obtrusive.

To communicate with the person with cataracts, arrange yourselves so that she does not have the sun in her eyes. She may not be able to read sign (especially fingerspelling) from across the room, but may need to move somewhat closer.

Cataracts usually only occurs in elderly people but those with RP often get cataracts in their thirties.

Glaucoma

Fluid builds up within the eye which can damage the retina. It is operable. If untreated however, or if it is particularly severe, it can cause partial to complete blindness. People with glaucoma function with what is called close vision.

Close Vision

As opposed to the person with tunnel vision, the field (range from left to right and top to bottom) of vision is unimpaired, but the clarity of vision, the acuity, is not good. A person with "close vision" needs signing to be exceptionally close in order to see it well enough to understand. "Close" might mean within ten to twelve feet, or "close" might mean no more than eight inches away.

Since our best vision is right in the middle, it makes sense to sign small. The person with close vision can indeed see on the sides, but it is so blurry that it is hard to recognize. Signing may have to be somewhat slower, but fingerspelling almost surely will.

Maternal Rubella

Most of us know rubella as a cause of deafness. It also can and does cause blindness or deaf-blindness. This blindness may leave the person with "close vision" or more severely blind.

Many, but certainly not all people who are deaf and blind from rubella (a form of measles contracted by the mother during early pregnancy) also have cognitive impairments.

Optic Atrophy

Sometimes called optic nerve atrophy (OA or ONA) is, just as it says, a deterioration of the optic nerve. There are many kinds of ONA. Some are hereditary, many not. There is a very rare hereditary form that causes congenital deafness and progressive blindness from ONA. I know of only three such families although I am sure there are more. It seems to be extremely rare. There also seems to be another syndrome combining progressive nerve hearing loss with progressive blindness from ONA. I have met less than a half dozen deaf-blind people with such a history. In each case, the cause of both hearing loss and the ONA was unknown.

A person with ONA gradually needs signing closer and closer until finally (in old age) even very close is not enough. The deaf person with ONA may not seem very blind and it is easy to overlook the fact that they cannot effectively participate in meetings (where the chairperson is 15-20 feet away) classes, workshops and so on where signing must be seen at a distance. They cannot watch live ball games, or drive, and they miss out on social information. It also gets increasingly easy to get lost or disoriented as the person sees less and less of the surrounding context. The ease with which a person with ONA can "pass" for many years supports any inclination they might have to deny their blindness. As deaf-blindness becomes more visible, and deaf-blind people more active, more deaf-blind people with ONA begin to speak up and identify themselves as deaf-blind.

Blind: legally, blind, totally blind, "blind-tactile"

This is a relative term. Just as the term "deaf" is a general term used to refer to many people who have varying degrees of hearing loss, so too the term blind is a cover term. Legally, the definition of blindness is either acuity less than 20/200 or a field of vision less than 20 degrees. Normal vision (20/20) means that this person sees at 20 feet what a "normal eye" sees at 20 feet. Vision of 20/200 then means that what this person sees at 20 feet, a "normal eye" is able to see at 200 feet. A normal field of vision is 180 degrees from side to side and top to bottom. Twenty degrees of vision is thus about ten percent of normal.

The term deaf-blind is also a social term. People identify themselves as belonging to the group by these terms as well. Just as deaf people call themselves deaf or hard of hearing without meaning actual decibel loss, so too deaf-blind people sometimes call themselves deaf-blind or "Usher syndrome" or tunnel vision more as a social identity than a description of their vision.

Sometimes a deaf-blind person is additionally identified in sign and English as "full/totally" blind. Sometimes this clarification is used to indicate communication preference to be both tactile sign and Braille. Sometimes it is used to identify the level of challenges facing such a person.

Some people with Usher syndrome have such a narrow tunnel that they cannot see sign comfortably, and thus prefer hands-on or tactile signing, but are still able to read dark print and use their vision to help them travel, e.g., to see traffic signals. These people are not usually called "full/totally" blind but in ASL and English as "Blind tactile" or simply "tactile."

The point here is that as the term "deaf" is inclusive but identifies a need for special consideration vis a vis communication, so too the term "blind" is inclusive and identifies a need for special consideration vis a vis both communication (if they are deaf) and mobility or travel.

Tactile/Tactual

Although they are often confused, tactile is equivalent to visible (refers to a quality of the object) while tactual is equivalent to visual (refers to the process). It is a fine point and most people do not make the distinction.

Used in the term "tactile signing", it

identifies the object (e.g. signing) rather than the language or process which may seem redundant. It clarifies that the deaf (blind) person is understanding signs by touch rather than vision. Usually this is done by the listener placing her hands on those of the signer.

"Tactual interpreting", "tactual communication" "reading signs tactually" etc. then describes the process rather than the language, etc.

Tracking

Understanding signs by touch and vision together. Usually the deaf-blind person places their listening hand on the wrist or upper arm of the dominant hand of the signer. This helps their eyes focus and "track" the hands of the signer visually.

Some people with RP always prefer to use their vision as much as possible, moving always to better lighting and only gradually changing from reading signs visually to tracking to tactual as their vision deteriorates. Other deaf-blind people (usually those with the support of a good deaf-blind community) are more comfortable with touch and move back and forth between tactual and visual reading of signs depending on how close people are, the brightness of the lighting, etc.

Some people will skip or move right past the tracking step and begin using their hands for tactual signing while using their remaining vision to watch the signer face for grammatical signals there, for speech reading (or even to look around the room at the reactions of others, etc.)

Finally, some people with RP (usually Usher Type II) have only lately learned to sign at all. These people do not understand signs in any form readily, and depend on a full combination of lipreading and feeling signs tactually.

Small Group Interpreting

Some deaf-blind people with or without tunnel vision, have poor visual acuity. This can be caused by cataracts, optic atrophy, or other "eye problems." Their central vision is fuzzy or blurry. This makes it difficult to read print. It also means they cannot see well at a distance. People with very poor acuity cannot see a platform interpreter because s/he is too far away, hence the need for "small (close) group" interpreting.

For people who have both tunnel vision and poor acuity, optimal communication (still facilitated by appropriate background, etc.) is signing which is both small and far enough away to see the whole sign and both slow and close enough to have some clarity. This is typically 4-6 feet away. These people too, require small group interpreting.

A few deaf-blind people need signs very close - anywhere from six inches to three feet away. In this case, a "small group" will consist of only one or two people, and is often just called close vision interpreting.

Voice

Short for "sign to voice interpret." Interpret from signed ASL or English-like signing into spoken English.

Voice to Sign

Interpret from spoken English to ASL or English-like signing.

Copy Sign

Repeat (in sign) what someone else is signing (i.e. from sign to sign). This is necessary for people who may not be able to see the signer because they are too far away, the lighting is poor, they are wearing light colored clothing, or because they are signing in too large an area for the listener's visual field.

Signed dialogue or conversation which

moves back and forth at a normal pace is too fast for a person with RP to follow (track) visually. They would soon be lost and left out of such a conversation. This would be an instance in which an interpreter would copy sign.

This term is also used to describe what an interpreter does who watches a presenter using sign and copies it into the hands of a deaf-blind person reading signs tactually. Such a person is sometimes called a "relay interpreter".

HERE AND THERE

THE ULTIMATE HANDBOOK: RECREATION AND SPORT FOR PEOPLE WHO ARE BLIND OR VISUALLY IMPAIRED by Peter Richards, is a guide to adaptations for improving accessibility to indoor and outdoor activities for people who are blind or visually impaired. The 84-page handbook, published by Vision Australia Foundation, costs $27.50 AUS and is available in print, cassette and Braille. For more information, contact Vision Australia Foundation, 011-61-03-9864-9222 or write to them at 7 Mair Street, Brighton 3186, Australia.

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The MaxPort Viewing System is a self-contained magnification system that displays an image on the user's glasses rather than on a monitor. For this reason, it can be used in situations where portability or lack of space is an issue. The digital magnifier can be used on any surface, i.e., books, cans, display panels. It features three contrast views: photo, negative, and positive. There are also magnification and brightness controls. The glasses weigh four ounces with no assembly required. The control unit and rechargeable battery provide three hours of continuous reading. Price: $1,495.00. For more information, contact: Enhanced Vision System, 130 Main Street, Suite 250, Huntington Beach, CA 92648. Telephone: (800) 440-9476.

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GW Micro, Inc. has released Window-Eyes 4.00, which offers braille support for a wide range of applications and operating systems including Windows 9x and ME. Contact: GW Micro, Inc., 725 Airport North Office Park, Fort Wayne, IN 46825. Telephone: (219) 489-1671.

****

The Braille Group of Buffalo, New York, has received a grant from the Josephine Goodyear Foundation to provide diabetes publications in Braille. For more information, contact: Jill Pariso, Diabetes Braille Project, Braille Group of Buffalo, 4660 Sheridan

Drive, Buffalo, NY 14212. Telephone: (800) 561-8252.

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Shell World, designed specifically for blind and deaf-blind computer users, now provides dial-up shell and POP accounts. Ken Scott, who is blind, is the owner of Shell World Internet Services and can provide technical support from a blindness perspective. Accounts include 56K access and a 50-MB disk quote. Those who wish to have a POP dial-up account can get a shell, accessible from the POP account, at no extra charge. The POP account costs $19.95 per month. To find out if Shell World has an access number in your area, visit http:www.shellworld.netandlocations.html Numbers are available in the United States and Canada. For more information, E-mail admin@shellworld.net

If you are interested in tactile maps and drawings, the Princeton Braillists, long known for their excellent tactile maps, will send braille information describing their maps to interested individuals. Among the maps/atlases currently available are: a two-volume sets of Atlas of Western Europe, Atlas of North and South America, Atlas of the Middle East, Atlas of the Bible Lands, Atlas of the British Isles, and Basic Human Anatomy (drawings). Prices range between $10.00 and $50.00; purchase orders from agencies are accepted, but not credit cards. To order, or for more information, call (732) 350-3708, or write to: The Princeton Braillists, 28-B Portsmouth Street, Whiting, NJ 08759.

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Readers may be interested in a new braille service that has been operational for about a year. HotBraille is a free braille service. You can send braille messages to anyone around the world in both Grade One and Grade Two Braille - and in nineteen languages. Messages are processed the same day that they are received online and sent the next day. Letters will be postage-free as long as they are less than four pages in length in braille (approximately 500 words or 1-1/2 pages in print). Sending a message by HotBraille is as private as sending one by E-mail. To sign up for this free service, go to: www.hotbraille.com

NAT-CENT NEWS

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FOR DEAF-BLIND
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EDITORIAL
TWO WOMEN

By Robert J. Smithdas, LHD, Litt.D, LHD

More than 150 years have passed since Dr. Samuel Gridley Howe, founder of Perkins School for the Blind in Massachusetts, began teaching Laura Bridgman, the first deaf-blind child to be taught in the United States, the meaning of language and how she could function as a social human being despite the loss of both sight and hearing.

Dr. Howe's achievement in educating Laura and making her aware of the real world in which she moved, has always fascinated me because he had no precedents from which to learn the necessary techniques to use in overcoming the formidable problem of giving Laura a personality and an awareness. His pioneering zeal was the beginning of progress in work for and with the deaf-blind in this country.

The story of Helen Keller often overshadows Laura Bridgman's success. There were basic differences between the two women's personalities - Laura, who preferred privacy and Helen, who enjoyed cosmopolitan society and world travel.

Little has been written about Laura who grew up in the mid-nineteenth century and was content to lead an ordinary community life, while Helen was by far more outgoing and ambitious and lived during a long period of social and economic growth into the late years of the present century. But the lives of both women stand out as landmarks that testify to exceptional achievements that have led to a host of programs and services which provide new horizons for deaf-blind people in many nations.

I wonder what the next hundred years will produce? There always has to be a new beginning!

NEW REGIONAL REPRESENTATIVE

Reprinted from the HKNC Affiliate Newsletter

Although we said goodbye to our affiliate contact person at the California School for Professional Psychology in San Diego, we do not loose this valuable person!

We welcome Michael Brennan to the Helen Keller National Center, recently taking the position as Mid-Atlantic Regional Representative covering New York, New Jersey, Puerto Rico and the Virgin Islands.

We also welcome Kathy Brennan (name coincidence? No - it's Michael's wife!) as the new administrative assistant to both the Regional Representative and Affiliate Coordinator. Welcome both Brennans!

SPOTLIGHT ON PATTY STARR AT THE HELEN KELLER NATIONAL CENTER

Reprinted from the Deaf Rochester News June/July 2001

Patty Starr at HKNC with Robert Smithdas

As a deaf person with Usher syndrome, I spent eight weeks of training at the Helen Keller National Center (HKNC). Being there was such a rewarding experience that I wish to share my stories (and tips) with all of you, especially to those with vision impairments who may be unsure about going to HKNC.

HKNC is located on a beautiful 25 acre campus in Sands Point, New York (Long Island) with a Training Building and a

Residence Hall. There are nearly 100 hard-working and dedicated staff and instructors, some of whom are deaf. Approximately forty deaf and hard of hearing adults with various vision impairments, participate as students undergoing a wide variety of training and rehabilitation to regain their independence.

When I first arrived at HKNC last January, a number of students at the Residence Hall quickly approached me, their hands eagerly trying to find my hands, and began to introduce themselves by tactile sign language. I was a bit overwhelmed because I had never been associated with the deaf-blind community before.

TIP NUMBER 1: When using tactile communication, always begin by spelling your name so that the deaf-blind person will know who he or she is talking to. My new roommate, Agatha, a feisty deaf woman from

New Jersey, has Usher syndrome and we exchanged many of our experiences and frustrations. Unbeknownst to me, this was the beginning of late, late night chats with many people at HKNC. It was just like the old college days!

TIP NUMBER 2: Set your watch's vibrating alarm at 11 PM to get ready for bed, otherwise you won't realize it's 1 or 2 AM in the morning. During the first several days I underwent a series of intake evaluations and assessments in order to determine what areas of training were needed.

Time flew! There were millions of questions, hours of discussions and brainstorming ideas and plans with my case manager and so many staff in all the different departments. After the evaluation period, training goals were then developed and implemented.

TIP NUMBER 3: Always bring a notebook to take notes! I took many

Independent Living Skills classes to learn how to prepare and cook food, to do the housecleaning and the laundry. This may sound routine to you, but try cutting up meats and vegetables, measuring and mixing ingredients and cooking while being blindfolded!

I had to learn reading Braille on canned foods or containers, including the entire spice rack. I prepared six different recipes and they were delicious.

TIP NUMBER 4: Don't try this at home until you've been properly trained with special techniques! I tried out several safety-related aids and devices. It was amazing. I wore a personal pager for home safety like fire alarms, doorbell, telephone and environmental sounds. There was a small vibrating device that tells you to stop pouring when it is nearly full. There are all kinds of labeling systems for household cleaning products. All of these things have enabled me to become much more independent around my home.

TIP NUMBER 5: While I was away from home for eight weeks, my husband also learned new independent skills as well. He finally learned how to cook, do the laundry and clean around the house! If your husband (or your kids) don't help around the house, go to HKNC! The Mobility and Orientation program taught me how to learn safe traveling skills on the stairs, elevators, escalators in stores, and broken sidewalks around the block when I visited a small town nearby. The use of a cane does the trick for me. When I go to the mall, people really move out of the way. I am much more relaxed when I travel with my cane. Without it, it can be quite stressful trying to watch where you're going.

TIP NUMBER 6: When you are near the administrative offices at HKNC, watch out for the boss! One day, a deaf-blind gentleman bumped into me in one of the hallways of the Training Building. He was the Assistant

Director of HKNC! Utilizing tactile communication, I inquired as to why he was not using the cane. His response was that he doesn't use it at work which I thought was unusual, but he's very proud of himself as well as HKNC.

Prior to going to HKNC, I did have the opportunity to learn mobility and orientation from Nikki Llewlyn at the Association for the Blind and Visually Impaired-Goodwill. She learned sign language at MCAHI and was extremely helpful in getting me started using the cane and learning how to take the buses to various destinations in the city.

The Communication Learning Center offered so many options to choose from for my unique needs. I began the difficult task of learning Braille with a deaf-blind teacher. She was a great role model. I was shown different devices like large print TTY, Perkins Braille typewriter, writing guides and many more.

You must constantly practice Braille, or you will lose the skill - like we tell hearing folks to practice sign language!

The Vocational Services Program helped me map out my potential of becoming a deaf-blind consultant for the Rochester community. I took a course in Public Speaking and had the opportunity to work in HKNC's Public Relations office. I have given a number of presentations to some high schools on Long Island and to visitors from out of town who were contemplating entering the HKNC program in the near future.

The Adaptive Technology Department showed me various kinds of computers with windows so that deaf-blind people can read better and not use the mouse cursor. That was so cool!

The Low Vision Program allowed me to try many low vision aids such as magnifiers, different colored sunglasses, lamps with dimmers, portable CCTV's and more.

In the Audiology Program, I tried on different hearing aids. I was shocked to hear how loud a toilet flushes! I may consider getting hearing aids as a means of hearing environmental sounds (dropping something, door closing, etc). Understanding speech with hearing aids was not an option for me. We did have a discussion about the possibility of getting a cochlear implant (CI). I politely declined - however, CI can be a very viable option for folks with Usher syndrome II. This syndrome is different from my condition; it mainly affects hard-of-hearing people.

HKNC also provided health classes, Usher's support group meetings, and student run Town Hall meetings. As you can see, having a notebook with you is important! You'll never have a "slow day" at HKNC!

On evenings and weekends, the Residence Hall staff provided many activities like bingo, arts and crafts, aerobics, field trips to NYC, beaches, shopping and going to open captioned movies. In Creative Arts, I made two macrames, and it is just for fun and relaxing! All activities are accompanied by SSP (Support Service Personnel). They are either paid staff or volunteers that guide deaf-blind during excursions.

Leaving HKNC was sad for me because I made so many new friends there. But, without question, I'm sure glad to be home with my family, especially with my humorous husband, Matt.

As an HKNC alumnus, I will have opportunities to attend future conferences sponsored by the American Association of Deaf-Blind. I look forward to working with Rochester-based Deaf-Blind Collaborative and to improve the quality of life for deaf-blind Rochesterians.

Please be on the lookout for future announcements about deaf-blind services and programs at Rochester.

For more information about HKNC, call

516-944-8637 (TTY, 516-944-8900 voice or e-mail at hkncintake@aol.com

THE OHIO DEAF-BLIND OUTREACH PROGRAM

By Dr. Jeffrey Bohrman
Reprinted from the
HKNC Affiliate Newsletter

NOTE: The Ohio Deaf-Blind Outreach Program (ODBOP) has recently completed its funding cycle as an HKNC Affiliate. This project, under the auspice of The Columbus Speech and Hearing Center and headed by Dr. Jeffery Bohrman, began in the spring of 1996. As part of their final report requirements to the HKNC Affiliate Program, Jeff submitted the following wrap-up of some of the accomplishments of the project:

To date, ODBOP has identified approximately 900 individuals who are deaf-blind in Ohio ranging from the ages of 15 years and older. They are currently working on re-doing the census.

From 1997-2000, ODBOP served 232 consumers who are deaf-blind and have a wide variety of backgrounds. From 1998 - 2000, ODBOP had 31 job placements and 61 "job saves" (examples of job saves include equipment assessments, equipment repairs, communication assistance, safety assessments).

Members of the staff have attended a number of seminars at HKNC as well as attending many trainings and/or workshops at Northern Illinois University and on a local basis.

ODBOP staff provided numerous in-service trainings to various agencies, programs, companies, and residential areas including group and nursing homes. Among the topics being addressed were: etiologies of deaf-blindness, communication, basic orientation and mobility, and recreational activities. Staff also conducted sensitivity awareness training for employers and coworkers of consumers.

The program has continuously marketed at the offices of Bureau of Services for Visually Impaired, service agencies including Goodwill Industries, community mental health centers, vocational training centers, schools and universities, retirement centers and nursing homes, agencies providing services for older adults, blind associations and community centers for the deaf and others.

As a result of marketing efforts, ODBOP implemented a "fee-for-services." They now provide limited SSP services, communication and equipment evaluation and/or training for some clients. Such services are being targeted to address the needs of individuals who have fallen through the cracks since their needs do not include vocational services.

ODBOP initiated quarterly meetings for consumers in 1994, and then in 1998 formally became the Ohio Association for the Deaf-

Blind (OADB).

The advisory board has held meetings regularly, now on a semi-annual basis. ODBOP is actively involved in the interagency task force group known as Ohio Interest Group on Individuals with Deaf-Blindness that meets on a quarterly basis.

On behalf of ODBOP and the entire Columbus Speech and Hearing Center, we would like to thank you and the staff at HKNC for the commemorative plaque acknowledging our past five years of service. We truly enjoy and appreciate the opportunity of being an HKNC affiliate. ODBOP has benefitted tremendously from this affiliation. We look forward to continuing and strengthening our affiliation with HKNC and other HKNC affiliates around the country.

LAURA BRIDGMAN'S WORLD

By Louis Menand (Reprinted from The New Yorker, July, 2001)

The house in which Laura Bridgman was born, in 1829, sits on a remote dirt road in a tiny New Hampshire village, now called Etna, on the outskirts of Hanover. The Bridgmans were farmers; they were also evangelical Baptists, and it is possible to imagine, driving by their farm, on the edge of a mountain, or walking through the small, hilly graveyard nearby, where the family is buried, how hard and how narrowly focused their lives must have been.

In the winter of 1832, when Laura had just turned two, the family was stricken with scarlet fever. Two of the children died, and though Laura survived, it was a close call. Her convalescence took two years, and by the time she was able to walk again she had lost all the sight in one eye and almost all in the other; she retained only the faintest sense of taste and smell; and she was completely deaf.

The little sight she had was destroyed when (horribly) she punctured the eyeball by walking into a spindle projecting from her mother's spinning wheel. She had long since stopped talking. She was five, and had only two attenuated senses and one intact sense - touch - left to her. Later on, though, after she learned to express herself by using a manual alphabet (pressing her fingers into the hand of her interlocutor), she used to say that she had in fact four senses: taste, smell, touch, and what she called the sense of "think." It is a brilliant remark, for it sums up, in its ingenuous way, one of the meanings of her story.

During the course of her lifetime - she lived to be fifty-nine - many people claimed to have discovered the meaning of the Laura Bridgman story. The principal figure among these was the man who (in his own rendering of events) rescued her from her remote farmhouse and her parents' fundamentalism, carried her off to enlightened, Unitarian Boston, and restored her to humanity by conferring on her the gift of language.

This was Samuel Gridley Howe, a veteran of the Greek Revolution (in which Byron, his hero, had died), a Christian reformer, and, later on, a financial backer of the abolitionist kamikaze, John Brown, and the husband of the author of "The Battle Hymn of the Republic." In 1837, when he went to New Hampshire to find Bridgman and bring her back to Boston, Howe had just been appointed director of the new Perkins Institution for the Blind. He had been on the lookout for a student who was both blind and deaf when he heard about Laura through a professor at the Dartmouth Medical School. He was quick to recruit her.

Her parents, unable to educate her, were happy to see their daughter taken off to

Boston under the care of the dashing and high-minded Dr. Howe. For six years, Howe made Bridgman the poster child of his efforts to reform the education of blind children in the United States, and she proved an exceptional student. No deaf and blind person had ever been taught to read and to "speak" before, and she was regularly exhibited to audiences of potential donors to Perkins, before whom she displayed her remarkable accomplishments, among them the ability to recognize, by the touch of the hand, people she had not "seen" in many months.

By 1842, after Charles Dickens devoted a long chapter to her acquirements in "American Notes" (he ranked her, with Niagara Falls, as one of the two most impressive phenomena he had witnessed on his trip to the United States), Bridgman was an international celebrity. Little girls poked out the eyes of their dolls and named them Laura. Howe was a celebrity too. Their names, like those of Helen Keller and Annie Sullivan sixty years later, became inextricably joined.

By some strange (and, to the authors, possibly unwelcome) serendipity, two books about Bridgman and Howe have just appeared. Ernest Freeberg's "The Education of Laura Bridgman: First Deaf and Blind Person to Learn Language" (Harvard; $27.95) puts the emphasis on Howe and his ideas; Elisabeth Gitter's "The Imprisoned Guest: Samuel Howe and Laura Bridgman, the Original Deaf-Blind Girl" (Farrar, Straus and Giroux; $26.00) is closer to a biography of Bridgman. Both books are discriminating without being anachronistically judgmental.

Gitter's writing is more dramatic and speculative (she is an English professor: speculation is something English professors are good at), and her book is not only informative but affecting. What a reader wants, after all, is to gain some feeling of what it might have been like to be Laura Bridgman.

Probably no sighted and hearing person can ever accurately convey that feeling, but Gitter gets us in what seems the right neighborhood.

As both books reveal, Howe was, in some respects, a vain and peremptory man, and he was no philosopher. He was handsome and combative, and he knew how to raise money; he might easily have enjoyed a great career in business or politics. But it accorded with his sense of self-importance, in prewar Brahmin Boston, to devote himself almost fanatically to doing good, and although many of his educational techniques now seem not only wrongheaded but inhumane (he sometimes disciplined blind children by handcuffing them), he was an inspired teacher. For he did devise a method for teaching an eight-year-old blind and deaf girl how to communicate with other people.

Howe was not a believer in Sign, the language for deaf people which had already been developed in France and was being championed by Thomas Gallaudet, the director of the American Asylum for the Deaf and Dumb, in Hartford, Connecticut. Howe thought that Sign was just a primitive kind of pantomime, and, in the beginning, a central tenet of his theory of education was that blind children should be taught as much as possible in the manner in which sighted children are taught, and this meant teaching them the English-language alphabet. He therefore printed books with raised letters (the volumes were enormous), which his students learned to read with their fingers.

In Laura's case, of course, he couldn't tell her what the words she was feeling with her fingers meant. So he began by placing the raised letters that make up words like "key" and "spoon" next to the objects they refer to, and laboriously moving Laura's fingers from the word to the object and back again.

In reports that Howe wrote later, there was a eureka moment. At first, he wrote, "it was as though she were under water, and we (her teachers) on the surface over her, unable to see her, but dropping a line, and moving it about here and there, hoping it might touch her hand, so that she would grasp it instinctively."

Then, after months of fishing, Laura bit. She suddenly got language. "Her countenance lighted up with human expression; it was no longer a dog or parrot - it was an immortal spirit, eagerly seizing upon a new link of union with other spirits! I could almost fix upon the moment when this truth dawned upon her mind, and spread its light to her countenance. I saw that the great obstacle was overcome."

Freeberg is skeptical of this epiphanic account - he thinks the process was much more arduous and gradual - and he and Gitter are both dubious of Howe's assumption that Laura retained no residual understanding of language from her early childhood. It seems likely, as Gitter suggests, that her brain had at least been imprinted with a capacity for grammar before she came down with scarlet fever. She was, eventually, comfortable using the subjunctive, the conditional, plurals, conceptual terms, and a number of other linguistic forms that are extremely unusual among deaf and blind people who had no exposure to language.

But the notion that he had turned Laura on to language, like flipping a switch, was crucial to Howe's larger agenda. That agenda was a characteristically Victorian conflation of science and spirituality, a kind of materialist "proof" of divine design, like natural theology.

The scientific and materialist component was phrenology: the belief that minds come equipped with certain "faculties" (twenty-seven of them, according to the founder of phrenology, Franz Josef Gall), such as veneration, acquisitiveness, secretiveness, hope, combativeness, linguistic perception, form conception, size conception, and so on.

These mental faculties (this is the materialist side of the theory) are manifested by physical bumps on the skull, so that religious persons have larger veneration bumps than skeptics, bullies have larger combativeness bumps than sissies, and so forth.

What is more (and this is probably the source of the theory's appeal to the Victorian mind: the fussy-orderliness element), the bumps are arranged hierarchically, so that the basic faculties of perception (the ability to perceive form or space or causality, for example) are lower down in the brain (and the bumps are lower down on the head), and the higher faculties, such as veneration and benevolence, are on the top.

Howe's faith in phrenological science was so great that he seems to have decided to marry, at the age of forty-two, because a phrenologist friend told him that he possessed a large affection bump and it would be bad for his health not to find an object on which to exercise it. (Julia Ward, as it turned out, was the wrong object; she was much too independent-minded for the upright and chauvinistic Dr. Howe, and the marriage was deeply unhappy. According to Gitter, Julia regularly kicked her husband out of bed - which sort of knocks a hole in the faculty-of-affection theory. It's not how big your bump is, apparently, but what you do with it that counts.)

This all sounds materialist and determinist enough, but phrenology was used to make an anti-materialist point. It was taken up by Howe and his fellow-enthusiasts to refute what they regarded as a truly materialist and determinist account of the mind, the account provided in the philosophy of John Locke.

In the Lockean theory of knowledge, minds come equipped with no contents at all. They are, in the famous phrase, tabulae rasae - bland slates. Everything we think and know comes through the senses; nothing is innate.

Locke was a religious man, but to many people his theory seemed to turn human beings from God's special creatures into fancy versions of the brutes, from conscious moral agents into the toys of matter. A theory, like phrenology, that argued, with scientific evidence, that mental contents are innate was a theory consistent with the belief in a divine creator. God, not the environment, gave us our characters.

It is easy to understand why a deaf and blind girl was the ideal experimental subject for a man like Howe. If he could show that her faculties developed with only minimal sensory input, she might serve as a standing refutation of Lockean materialism. She might establish the existence of the soul. "The immortal spirit within her, although in darkness and stillness like that of a tomb," Howe wrote at the very beginning of his work with Laura, "is full of life and vigor, is animated by innate power and triumphantly refutes the doctrine that the soul is but a blank sheet upon which education and experience write everything." This is why Howe insisted on representing Laura's acquisition of language as an almost spontaneous event: he wanted to be able to claim that he had simply activated her latent language faculty.

In the end, Howe's loyalty to phrenology was his experiment's undoing. Since the bumps associated with spirituality are at the top of the head, Howe was careful to prevent Laura from receiving any information about religion until he felt that she was ready for it.

He wanted, when the time came, to demonstrate in the case of religious feeling what he believed he had demonstrated in the case of language - that the love of God, like linguistic competence, is innate. His plan was to introduce his pupil to the subject in a way analogous to the procedure he had used with words. He would place before her evidence of nature's beauty and design - showing her, for example, how plants grow from seeds - with the expectation that one day the switch would be flipped, and she would spontaneously intuit the existence of a divine First Cause.

Keeping information about religion from Laura turned out to be very hard to do. For one thing, she was an incessantly curious person. She wore out her teachers with questions. " Why do flies not have names, like boys and girls do? Is the worm afraid when the hen eats him? Why do cows have two horns? To push two cows? Why can't we sail to the sun ‘in boats’? If I eat fish hooks, could I be dead?" And on and on. She had a strict regimen of schoolwork, but what she really wanted to do was sit and spell questions into her teacher's hand hour after hour.

There is not much doubt that this inextinguishable curiosity is what inspired her to master reading and writing well beyond the limits of necessity. It is possibly even what kept her alive. (When she was unhappy, she starved herself). But she was a compulsively fastidious person generally -"birdlike" seems to have been a common description. She was particular about her clothes; she cleaned her room meticulously; at one point, she requested a mirror. A psychologist who observed her late in her life, G. Stanley Hall, thought that there was something pathological about her curiosity; and Gitter suggests that Laura may have developed, as a consequence of the scarlet fever, a condition of obsessive compulsion known as pediatric autoimmune neuropsychiatric disorders associated with streptococci. The notion that Laura was (beyond her obvious sensory deprivation) medically exceptional was, of course, a notion Howe wished to avoid.

Another reason that Howe wanted to postpone Laura's religious instruction had to do with his Unitarianism. He regarded the Calvinist obsession with sin and sacrifice as a superstition, and he didn't want his prize pupil's head filled with gloomy fundamentalist dogma. Indeed, that the natural religious instinct is free of gloom and dogma is precisely what he hoped to show.

But in 1843, when Laura was thirteen, Howe got married, and he and Julia went to Europe, where they stayed for more than a year. He left Laura in the care of Mary Swift, a teacher who not share his liberal religious views, and, under the relentless pressure of Laura's curiosity, Swift allowed her student to be introduced to old-style religion. Laura wrote long letters to Howe asking him about God, but his answers were brief and evasive.

By the time he returned from Europe, the damage was done. "I hardly recognized the Laura I had known," he later complained. And he was quick, in his imperious manner, to declare her education a failure. He began to withdraw from her, and to withdraw as well from his earlier insistence that blind children are capable of leading normal lives.

By 1848, he was declaring that "the blind as a class, are inferior to other persons in mental power and ability." In a weird reversion to a kind of Calvinist fatalism, he now claimed that disability was an inherited punishment for the vice of the parents, and that blind children were better off left in the care of their families. The failure of Laura Bridgman's religious education, he later said, was the greatest disappointment of his life.

Laura spent her days almost continually in the presence of another person, usually a young woman assigned to be her tutor and companion. She naturally developed deep and affectionate attachments to these people, as she did to "Doctor," as she called Howe. When they went away, to marry or to take another job, she was crushed. She begged to go with them, sometimes offering to serve as a housemaid, and her fantasies of how she would minister to her friends are heartbreaking.

She imagined herself, she once wrote, with half a dozen wings along her back: "My legs would be so powerful to leap a great distance as well as the kangaroo. My arms could be of much utility. I wish so much to run of my accord as swiftly as my strength will allow me. I could visit all of my good friends. I should carry many little things to them for Miss Wight (her favorite teacher) and our friends with great pleasure."

As Laura grew older, though, her companions drifted away, and Howe was reluctant to commit the funds needed to find new ones. She was too old to be educated any longer; the experiment was finished. She began regularly visiting her family in New Hampshire.

In 1862, when she was thirty-two, she was baptized, by immersion, in a brook near her parents' house, and she became a pious evangelical Christian. She lived another twenty-seven years, still famous but no longer a phenomenon. She commuted between the Perkins Institution and Hanover. She became close to one of her sisters, but the sister died, and in the last years of her life she had no true intimate companions.

Outsiders found her odd and unappealing. Much of her talk was about Christ and Heaven ("a good place that God knew that I could not fall off the edge of the floor," she had once described it). She wrote poetry ("A good sleep is a white curtain/A bad sleep is a black curtain"), knitted and crocheted. In 1888, she was introduced to the young Helen Keller, who annoyed her by stepping on her foot. A year later, she died. The last word she spelled was "mother."

Laura Bridgman received her education in an era when no distinction was generally made between psychology and moral philosophy. It seemed obvious that science would confirm conclusions that had already been reached by abstract reasoning or handed down by

Scripture - for example, that the ability to feel veneration is a "higher" attribute than the ability to perceive three-dimensional space. Phrenology was a particularly crude instance of this tendency, and it was derided by some scientists even in its own time. But Franz Josef Gall was a distinguished neurologist, and he did not think that speculation about the moral order of the universe was beyond his ken as a scientist. Quite the contrary.

By the end of Bridgman's life, this had changed. The two fields split apart, and psychology became a laboratory science. Psychologists studied reaction times and sensory thresholds; they eschewed metaphysical questions.

G. Stanley Hall, the man who diagnosed Bridgman's curiosity as a form of mania, was one of the first of these New Psychologists (as experimental psychologists were known) in the United States. The tone of his account of Bridgman's personality, published in "Mind" (a leading journal of the New Psychology) in 1879, is clinical, unsentimental, and free of ostentatious moralizing - in almost every way the opposite of Howe's reports on Bridgman forty years earlier. As Freeberg nicely puts it, "Laura Bridgman's sense of balance became far more interesting than the sense of right and wrong."

But it is not so easy to keep philosophical questions out of psychology. Every account of the way the mind works seems to imply some theory of conduct, or some belief about what is important in life. This was certainly the view of the man who was Hall's teacher, and the first New Psychologist in the United States, William James. In 1904, James reviewed a biography of Bridgman written by two of Howe's daughters.

The case presented many opportunities for psychological conjecture, he wrote, but "what is not conjecture, but fact, is the philosophical conclusion which we are forced to draw." By the standards of most people, James wrote, Bridgman's inner world was almost unimaginably impoverished and underpopulated. Her mental contents were restricted to tactile memories of the small number of things she could touch with her fingers, and to what James called "the pallidest verbal substitutes"- that is, written words.

Yet she found life as intensely absorbing as anyone else does. What this showed, James thought, was that the relations among things are far more interesting and important than the things themselves. "All sorts of terms can transport the mind with equal delight, provided they be woven into equally massive and far-reaching schemes and systems of relationship," he wrote. "The schemes and the systems," and not the pieces of information themselves, "are what the mind finds interesting."

This was a philosophical conclusion that suited James because it supported his view that there are many "realities" in the universe, each depending on where you start and what your material is, and that we sense relations as much as we sense things - that there is "a feeling of AND, a feeling of IF, a feeling of BUT, and a feeling of BY," as he once wrote.

But his remark also seems to echo Bridgman's own insistence that she had a fourth sense, the sense of "think." Thinking is an instinct as immediate and spontaneous as sight or touch: we can't stop doing it. It's the way we weave the sensuous tapestry of the world. From a cosmic point of view, all minds are pathetically underpopulated.

We somehow intuit a world from a tiny sample of what is out there - not as tiny as Laura Bridgman's but possibly not as great as we would like to imagine, either.

WITHOUT SIGHT OR HEARING, SCHOLAR KEPT HIS SENSE OF DETERMINATION

by Chie Matsumoto

Reprinted from the Asahi Shimbun News Service, Japan

Plunged into a world of darkness at the age of 9 and losing his hearing after turning 18, Satoshi Fukushima almost gave up hope. Even so, he had his senses about him. In fact, Fukushima focused on one sense in particular - a sense of determination to eliminate barriers for people like himself.

He is the first among the 20,000 deaf-blind in Japan to complete a doctorate program from Tokyo Metropolitan University. He entered the university in 1983. In April, Fukushima, 38, also became the first deaf-blind associate professor at theUniversity of Tokyo. Prior to that accomplishment, he worked at Yokohama National University, Tokyo Metropolitan University and Kanazawa University. But life has been anything but easy.

After losing his sight, he enrolled at the Tsukuba University School for the Blind. When he lost his hearing nine years later, he felt as if his whole world had collapsed. The Kobe native wrote about his experiences in a book titled "Morosha to Normalization" (Deaf-Blind People and Normalization), published in 1997. In it, Fukushima describes how his hearing slowly deteriorated as he listened to piano music. Eventually, the tones just disappeared.

When his mother punched Braille on a paper cup to describe a menu, he felt the world closing in. But the bright young teenager ended up changing the world around him instead.

Instructors at the Tsukuba school altered their teaching styles to accommodate

Fukushima, one of 15 students in the class, when he lost his hearing. Classmates practiced fingerspelling, hand signals that represent letters of the alphabet, and voluntarily translated lectures into Braille for their deaf-blind friend. "If it wasn't for his funny, interesting and well-balanced personality, he wouldn't have recovered from the shock of losing his hearing," said Vice Principal Osamu Shionoya, 58.

There are only few educational institutes in Japan for deaf-blind children. "He presented us with a rare opportunity," Shionoya said. "but I didn't have the slightest idea how to teach to satisfy his intellectual need." It was especially difficult for Fukushima, who received good schooling, to maintain his hunger for advanced education, Shionoya added. But he did and now it is Fukushima's turn to take to the podium and to help tear down the barriers for the disabled. "I want to take advantage of the minds from various fields gathered here in this department," Fukushima said in his office at University of Tokyo Research Center for Advanced Science and Technology.

When he was interviewed by The Asahi Shimbun, an assistant touched Fukushima's fingers in a pattern matching the Braille code so he could understand the questions. This method is called finger Braille. When Fukushima joined the university, he started working on a project to develop portable computers as a communication aid for the disabled. The computer, which looks like a Palm Pilot, will also help people in wheelchairs open doors, just like a remote control.

Fukushima and his team of eight researchers recently applied for a grant from the Ministry of Education, Culture, Sports, Science and Technology to develop the project. Desktop computers with Braille displays are available, but they cost 600,000 yen. He hopes his proposed project will help improve communication more economically, for the deaf-blind.

His motivation does not lie only in technology. It is also rooted in personal interaction and communication. "I believe there is nothing that can replace direct contact with people," Fukushima said. "Mechanics are important, but interpersonal communication is still necessary."

Fukushima also acts as an advocate for the disabled, both on and off campus. Disabled students need accessible facilities, counseling centers and services on campus, he said, adding that the university also needs to create a welcoming atmosphere for the disabled who want to enroll.

The Fundamental Law for People with Disabilities was revised in 1993, but Fukushima says it has brought little change in society. "It's just a slogan," he said. He said communication is the key to changing negative attitudes toward the disabled. "There are always limits to what you can learn from books and television," he said, adding that prejudices are perpetuated when there is no communication. If people study and work with the disabled, Fukushima said, they can learn from personal interaction, just as he did. "Just to roam on campus makes a difference for me," he said. "Students and faculty can see me walking with an assistant (so that he can communicate) and realize that people like me exist."

Satoshi Fukushima and Robert Smithdas use the Braille Lite as a means of communication during their meeting at HKNC.

Fukushima's appointment to his post as an associate professor encourages the disabled community said Yoshihiko Sasagawa, head of the Japan Federation of the Blind. Though the groups have not seen many drastic changes in society, Sasagawa said that Fukushima is often a hot topic of conversation. "His accomplishment is as valuable as that of Helen Keller," he said. "For the nation's 20,000 deaf-blind people and 350,000 deaf people, it is great encouragement and motivation." Krista Caudill, a 27-year-old computer science student at University of Delaware, also deaf and blind, has high hopes for Fukushima and what he can do for the deaf-blind in society. Caudill is said to resemble Helen Keller. Since Caudill met Fukushima at the American Association for the Deaf-Blind Convention in 1990, they have kept in touch communicating through e-mail on Braille display computers. "I know in my heart that Satoshi will continue to make life better for deaf-blind people in Japan and push for services that are needed to help them live independently," Caudill said via e-mail.

And that is exactly Fukushima's goal. "What I can do for the deaf-blind population has always been the purpose of my study," he said.

DEAF-BLINDNESS DOESN'T SLOW DESIRE

by Ryan McNeill

A peek into Melba June Barnett's apartment is a peek into a different world - a dark and quiet world.

A clock about 18 inches wide hangs on the wall to help her tell time, while a talking clock by her bed helps her hear it. If the phone rings or the fire alarm goes off at night, her bed shakes to wake her up. On her bookshelf rests several Bibles decorated with dust. "I used to read them all," she said. "But now I can't see them at all. Now they just sit over there."

Arts and crafts - including a crochet Braille symbol for "I love you" - adorn her walls and tables, adding color to a world she can't see.

Barnett, a 74-year-old grandmother of three, is one of more than 6,000 Oklahomans stricken with deaf-blindness, a condition combining legal blindness with a hearing loss that causes significant communication problems, according to the Oklahoma Department of Rehabilitative Services.

"The two disabilities are isolating," said Glenda Farnum, deaf-blindness specialist for the Rehabilitative Services Department. "The vision loss isolates them from seeing and the hearing loss isolates them from people."

At first glance, Barnett seems to fit that mold. She lives alone in an apartment. She hasn't worked in more than 40 years. She can't drive. She doesn't go to church. Reading or watching TV is difficult. "I used to get in my car and drive up and down those country roads," she said. "I used to go to the lake to go fishing or even another state. But now I can't do that anymore."

As for the Bibles on the wall, church is no longer an option. "My brother and sister-in-law used to take me to church," she said. "Now they can't take me. If someone wanted me to go with them, I'd go. I just don't know where to go."

Born with little hearing, Barnett began losing what she had in 1950. Her hearing loss forced her to quit her job making pancakes and waffles at a frozen food factory in Chickasaw. After her daughter married and started a family, she moved in with her and helped take care of her grand-daughters, now 17, 13, and 3. "I used to take them across the street to McDonald's," she said. "It was fun."

Eventually, the time came when Barnett wanted her own place, but it seemed like she was fighting the odds. The state of Oklahoma assisted Barnett's efforts in 1991 by sending her to the Helen Keller National Center in New York, where she was helped with her speech, walking with a cane and cooking.

"Deaf-blindness is a debilitating illness," Farnum said. "But it doesn't mean your life is over." Barnett is a testament to a life still going strong. "I love to make just about anything that is pretty enough to make," she said. "Things just pop up in my mind, and I make it."

Barnett makes dozens of arts and crafts, including crocheted works, hand-rolled paper houses, Christmas ornaments and key chains. Those wares have become so popular that she sells them at the craft fairs hosted by her senior citizens home. "I usually sell most of my stuff," she said. "People like them. But sometimes I just donate them."

Barnett also continues to cook. "I love to make hamburgers, meat loaf and soup," she said. "But it doesn't taste as good as it used to. I think I am losing my flavor."

Also easing the isolation is Abby, a gray cat given to Barnett by a veterinarian. "I love her so much," she said. "I just pet her and pet her. Sometimes I'll go make a phone call and she'll come in with me and listen to me."

Her activities combined with her desire to keep going, allow Barnett to keep functioning in a world meant for senses she doesn't have. "I might be doing too much," she said. "But I'll probably just keep going."

FINDING NEW TALENTS

Reprinted from the Braille Institute Newsletter

Scott Seigal, age 44, was born with Usher's syndrome, that causes deafness and retinitis pigmentosa, a progressive eye disease resulting in total blindness. Still able to read large print, Scott has learned braille to prepare for the day when all of his vision fades.

Working at the U.S. Department of Immigration for 12 years, Scott was at a loss when his department became computerized. Realizing that Scott was capable of accomplishing much more than the limited tasks he was left with, Scott's supervisor turned to the Braille Institute for a solution.

Our Career Services Job Developers analyzed Scott's job description, work station and equipment requirements. He needed large print software and a braille display allowing him to read the computer screen with electronic braille. Scott's supervisor also decided that Braille's 21-week Learning Center Program would give Scott the computer training and other skills necessary to expand his job responsibilities.

Today Scott is back at work, and is a proficient user of Windows, Microsoft Word and Excel. He keeps pace with his co-workers and does an outstanding job processing immigration applications, researching problems and performing other administrative duties.

PERCEPTIONS OF LIGHT

Reprinted from ABILITIES - Canada's
Lifestyle Magazine for People with
Disabilities, Summer 2001

Is light necessarily perceived by the sense of sight? "Perceptions of Light" by photographer Natalie Schonfeld, is a multimedia documentary about the everyday reality of people who are deafblind.

The body of work explores the existing channels of communication between each other and the outside world. The images of individuals using intervenors, immersing themselves in a lake, reading a Braille book, looking out a window, curling up on a bed - ordinary moments for people who are deafblind - are immensely intimate, emotional and beautiful as captured by Schonfeld.

Schonfeld began the project in 1997 as part of her thesis work while attending the Image Arts School at Ryerson University in Toronto, Canada. At that time, she was interested in learning about the Deaf culture. In particular, she recognized the parallels between sign language and photography as a means of visual expression. She began working at Toronto's Bob Rumball Centre for the Deaf, and came to know the deafblind senior residents.

"What has captivated me since that first meeting is their incredible strength, despite their constant struggle in a society that doesn't always meet their needs," says Schonfeld. "They are a celebration of life, even in the hardest moments."

Of "Perceptions of Light," Schonfeld says that the exhibition "is not only about deafblindness, or disabilities, or photography, or art - it is about challenging people's perceptions of themselves and one another, and inspiring action through different approaches to education. It is about bringing back sensitivity into people's lives; it is about re-connecting with our human selves - and transcending the boundaries imposed by our bodies, our nationalities and our religious differences."

Scholfeld's photographic eye travels to those individuals at the periphery, to that point at which the human senses take a step back to rearrange themselves. Chaos and struggle are the starting point in what becomes a rite of passage in the quest for liberation of the spirit.

As part of the fifth annual Toronto Photography Festival, "CONTACT 2001" in Toronto, "Perceptions of Light" was on exhibition at the Nathan Shiff Gallery in Toronto until June 2, 2001. It will also be exhibited in August, 2003, at the World Conference of Deafblindness in Mississauga, Ontario.

Schonfeld is encouraged by the support "Perceptions of Light" is already gathering from the community. In addition to very positive feedback from the deafblind community, the Canadian Abilities Foundation has agreed to accept donations on behalf of this initiative. The Image Arts Program at Ryerson University is also delighted to support this project, as it involves a new media approach to social documentary, a powerful tool for creating social awareness.

For more information, send e-mail to natalie@documentos-humanos.com. Other examples of Schonfeld's work can be found at www.documentos-humanos.com.

"My idea of light is how I feel things in the darkness." Bob Lock, deafblind resident at Bob Rumball Centre for the Deaf.

HERE AND THERE

KNOW ABOUT LOW VISION is a 22-page free booklet available from the National Eye Institute. Request the booklet by calling toll-free 1-877-569-8474. The publication can be downloaded from the website, www.nei.gov

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IF YOU ARE BLIND, OR HAVE LOW VISION, HOW WE CAN HELP is a publication from the Social Security Administration available in braille, print, audiocassette and on the Internet at www.ssa.gov.pubs 100052.html or call 1-800-772-1213 and ask for Publication 05-100052 in your preferred format. The Social Security Administration has also made the 2001 RED BOOK ON EMPLOYMENT SUPPORT: A SUMMARY GUIDE TO EMPLOYMENT SUPPORT AVAILABLE TO PEOPLE WITH DISABILITIES UNDER THE SOCIAL SECURITY DISABILITY INSURANCE AND SUPPLEMENTAL SECURITY INCOME PROGRAMS available. It is a joint effort sponsored by SSA, OPM, RSA, VA and state VR agencies. For more information, contact: Project ABLE, Social Security Administration, Room 107, Altmeyer Building, Baltimore, MD 21235-2401, or call 1-410-597-0429.

A new line of women's clothing, Dee-Dee, with braille and large-print labels, is now available at Henri Bendel department store in New York City. Dee-Dee Dot T-shirts, underwear and other clothing items are also available at www.deedeedot. Labels are said to withstand washer and dryer treatments.

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If you want to send a braille letter to anyone but you don't know braille, there is now a website that can help. HotBraille will transcribe your letter into Grade 2 Braille and send it to the addressee free of charge. HotBraille can process letters in 19 languages. Most of what HotBraille receives is processed the same day and sent the next day as "Free Matter for the Blind and Physically Handicapped. Visit HotBraille at the following website: www.hotbraille.com.

NAT-CENT NEWS

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EDITORIAL: BREAK THROUGH

By Robert J. Smithdas,
LHD, Litt.d, LHD

Years ago, while I was a high school student at Perkins School for the Blind in Watertown, Massachusetts, I went to its library and picked up a small braille volume entitled, "The Key," a brief biography of Laura Bridgman, the first deaf-blind child to be educated in this country.

A slim volume, the book contained less than fifty braille pages, written in a simple, straightforward style, describing how Laura had been educated by Dr. Samuel Gridley Howe, the founder of the school. Laura's story was told in general terms, leaving out much important information, and my curiosity was piqued. I asked the librarian for other books about Laura but was told there were no others.

Recently I learned that two biographies of Laura have been published. One of these books, "The Imprisoned Guest," by Elizabeth Gitter, has been carefully researched at Perkins School where the author spent months in the dusty archives housed in the basement of the school.

Miss Gitter writes that the longer she sat in the archives at Perkins, the more she was drawn to Laura's story and the world she lived in, surrounded by fascinating people. She writes that "In the twelve years since I first encountered Laura's writing, I have not been able to get her plaintive voice out of my head. I tell her story now so that Laura, silenced in life and often in history, can at least have her say."

It seems that now we may have a definitive biography of Laura Bridgman, who has until now been overshadowed by Helen Keller's accomplishments. But it makes one wonder why, with all the records and documentation about Laura stored at Perkins, no one thought to document the history of her life for over one hundred years.

Dr. Samuel Gridley Howe deserves recognition and acclaim for his pioneering work in the education of people who are deaf-blind. His efforts proved that Laura would overcome the vacuum and silence of her life and become a model for others who would follow. It was a new beginning for those who lose their sight and hearing. Helen Keller's mother learned of Howe's work with Laura, and Helen, in turn, became a legend through her exceptional achievements.

The book, published by Farrar, Straus and Giroux, costs $26.00 in print. Hopefully it will soon be published in braille.

LOVE AT FIRST BUMP

By Ellen Mitchell

Reprinted from Long Island Newsday

Bob and Michelle Smithdas ran into each other in a hallway 29 years ago. The deaf-blind couple teach the disabled to experience life to the fullest.

I only know that when I touch a
flower,
or feel the sun and wind upon my
face,
or hold your hand in mine,
there is a brightness
within my soul that words can never
trace.
I call it Life, and laugh with its
delight,
though life itself be out of sound and
sight.

The words are from "Shared Beauty," a poem written by Robert J.

Smithdas, and dedicated to his wife, Michelle Joanne Smithdas. The Smithdases are both deaf-blind. They have never seen one another, nor had either heard the other's voice until 1993, when Michelle underwent a cochlear implant and now is able to hear some sound.

To say the couple is extraordinary is to say the sky is a little more than a backdrop for the sun, the stars and the moon. He is an author, poet, lecturer, teacher, advocate for people who are deaf-blind, deep-sea fisherman, gardener, art collector and gourmet cook - for starters.

She is a teacher, writer, advocate for deaf-blind people, lecturer, exercise buff and cake baker. Both hold bachelor's and master's degrees. Both are recipients of honorary doctorates and numerous awards for their work in the training and rehabilitation of people who are deaf-blind.

Bob Smithdas is the director of the Community Education Department at the Helen Keller National Center for Deaf-Blind Youths and Adults in Sands Point. As part of his mission to raise community awareness of what people who are deaf-blind can do when given the proper opportunities, he gives lectures, arranges tours of the Center and edits a national newsletter.

Michelle Smithdas is an instructor

at the Center; she teaches people who are deaf-blind Braille, vocabulary, sign language and other communications skills. She is writing an instructional Braille book for deaf-blind people, because most Braille books are geared for people who are blind only.

The couple lives a relatively self-sufficient life in their Port Washington home. They travel extensively and enjoy a social circle that includes not only other deaf-blind people, but sighted and hearing friends as well.

Their mission is to teach people who are deaf-blind to live and work to the best of their capabilities and as independently as possible, and the way in which they have overcome adversity in their own lives is the best lesson they can offer. The fact that both have only three of the five senses that most of us take for granted each day is a remarkable testament to the resilience of the human spirit.

When I was a child, I used to stand
with a broken mirror in my hand
watching my laughing image pass
in and out of the shining glass.
If I could hold it here once more
and look into it as before,
I wonder if I still would see
a faint resemblance of Me?

From "Mirror" by Robert J. Smithdas.

Bob Smithdas, 76, was born near Pittsburgh. When asked his age, he responded with his signature dry wit, "I usually say I'm 1,000 years old. It seems to please people."

He lost his vision and most of his hearing at the age of 4 when he contracted cerebrospinal meningitis; his hearing regressed to the point that he was totally deaf by his mid-teens. "Unable to hear the sound of my own voice, I gradually lost my feeling for the pitch and stresses that give speech its human character," he wrote in his 1958 autobiography, "Life at My Fingertips." Any difficulties with speech have never been a deterrent to his amazing success. He articulates each word precisely and lectures extensively before audiences nationwide.

Bob Smithdas learned Braille and by his teens was an avid reader who "finished three or four books in a weekend." At 12, he began to write "not very good poetry, just rhymes," he said. He is a member of the Poetry Society of America, and was honored as their poet of the year in 1960. He learned to communicate through POP, the print-on-palm method of printing block letters on the palm of the hand. He is one of few deaf-blind persons skilled in the use of Tadoma, which enables him to place his right thumb on the lips of the speaker and his fingers over the vocal chords to interpret what is being said.

With the assistance of sighted, hearing friends who attended class with him and transcribed all his textbooks into Braille, Smithdas graduated cum laude from St. John's University in 1950. He was the first deaf-blind person to earn a college degree after Helen Keller. In 1953, he became the first deaf-blind person ever to earn a master's degree, which he completed at New York University in the field of vocational guidance and rehabilitation of the handicapped.

Michelle Smithdas was born in California with limited hearing, and was profoundly deaf by the age of

16. During the midwinter holiday of her senior year at Gallaudet University in Washington, D.C., the world's only university for people who are deaf, Michelle suffered a snowmobile accident which resulted in head injuries and her loss of vision. "It was devastating at the time and at that age," she said.

Despite the tragic turn in her life, she completed her bachelor's degree. (Some years later, she became the first deaf-blind person to receive a master's degree at an Ivy League university, earning a Master's in Education of Blind and Visually Impaired at Columbia University.) In 1972, she entered the training program at the Helen Keller National

Center where Bob Smithdas was already the director of community education.

Oh, when I reach to take you by the hand,
it is because I need to understand
that I am not alone in this broad land.
From "Touch," by R.J. Smithdas

"On my first day, I met Bob in the dark hallway. Most say love at first sight, but for us it was love at first bump in the dark. He was so good to make sure I did not fall down," Michelle Smithdas said.

The couple was married on December 12, 1975. "I would say my husband is very handsome. He is very strong and very intelligent. I am not totally blind," she added, "so I can sometimes catch parts of him with my little bit of vision. I put the parts together like a puzzle."

"I cannot describe my wife on a visual basis," Bob Smithdas said. "But she is very sweet, a lot of fun. She is petite and delicate and when she laughs she has a big smile. I go by my feelings, and they are strong for Michelle."

The couple communicates by fingerspelling their words, letter by letter, in the palm of the other's hand. They delight in one another as if they were newlyweds. She often defers to him. "It's very important that you listen to Bob," she said.

"Now you realize that she is a good wife," he said. The couple has no children. "No," Michelle Smithdas, 53, said. "Bob is enough. He is a big child."

Who does the cooking? "Bob cooks most of the time. He loves it and he is an excellent cook," she said. "Yes, I must be good. No one has died from my cooking," he said. A Polynesian chicken dish is his favorite. He also enjoys cooking Italian, Czech, Chinese and German foods. "I could write a cookbook, I guess," he acknowledged.

Friends and neighbors assist with food shopping and transportation. "I take them to the doctor," said Lynn

Dallesandro, who stopped by to visit. She first met the Smithdases when she worked as a volunteer at the Helen Keller Center in 1976. She is a nurse and able to explain things to the couple during doctor's visits. "We've become very good friends; they are awesome," said Dallesandro, who learned to finger-spell in order to communicate with them.

Her communication skills served well last year when Bob Smithdas underwent quadruple coronary bypass surgery. It has not slowed him down.

"Bob is an ox," said Joseph McNulty, executive director of the Center. "The other day, there was a freezer delivered to their house. Because the deliveryman couldn't communicate with Bob he left the freezer in the garage. Bob went back there and moved the thing into the house by himself."

Bob Smithdas was a wrestler in college. He now enjoys swimming and walking. "And I squeeze Michelle for exercise," he joked. He also does a lot of bending in the garden. "That reminds me, I have 50 bulbs to plant," he said.

His other interests include tinkering with old cars, the stock market and deep sea fishing. He recalls with fondness the 90-pound tuna he caught years back.

Michelle Smithdas is an exercise

enthusiast. She keeps a rowing machine and a stationary bike at home and watches her weight on a Braille scale.

The house in which the Smithdases have lived for 24 years is replete with computer technology. Their telephone takes typewritten input and provides Braille output, as does Michelle's computer. The couple wear pagers, which vibrate differently for the telephone, the doorbell or when one asks the other, "Where are you?" The stove and microwave have raised buttons to indicate an object ahead. They have vibrating sensors to indicate if the lights are on, to tell when to stop pouring liquid into a cup, and to recognize the denomination of bills.

As part of Bob Smithdas' job at the Center, he makes devices like these accessible to clients. He loves tinkering with gadgets, and is constantly working to improve on them.

Perhaps the most dramatic technological change in the couples lives has been the cochlear implant that Michelle Smithdas underwent in 1993. The device communicates some sound to the brain through electrodes in the middle ear.

"When I decided to try it, there was controversy between the deaf culture people and those going for the cochlear implants," she explained. "I was afraid some of those in the deaf culture would not continue to be my friends. Some people say you should accept what you were given by God, but I feel God wants an individual to use the advances in technology. Being a deaf-blind person can be quite isolating. You can only imagine what it is like to be sitting in a room, not seeing anybody, nobody stopping by and nobody calling on the telephone. So I decided to give it a try - and it is WONDERFUL.

While supportive of his wife's decision to undergo the procedure, Bob Smithdas has never taken tests to determine if he could be similarly helped. "No, I was pretty well seasoned in my own way of life. I didn't see the urgency in the cochlear implant," he said.

Always the small beginnings of great things:
always the pioneer who breaks the trail
across uncharted reaches of the mind
or through a trackless wilderness unknown.

From "Helen Keller's Legacy" by Robert Smithdas

An acquaintance of the Smithdases wrote a movie script some time ago that features the couple's lives and work and the level of achievement people who are deaf-blind can reach. Bob Smithdas hopes the money needed to produce the film can be raised. "They've produced 'The Miracle Worker' over and over again. But it's not telling the story of how deaf-blind people succeed today. It's important to know how we live in a modern environment. We feel blocked by the shadow of Helen Keller," he said.

"Many deaf-blind people have gone on to college. They are teachers, computer programmers and other types of specialists. A friend of mine is a mathematical whiz and owns his own computer business."

According to McNulty, the Helen Keller National Center is unique in this country. It focuses on clients' abilities rather than on the fact that they are deaf and blind. There are usually 40 students at a time; their length of stay ranges between several months and a year depending on their particular needs.

There has not been a nationwide count of deaf-blind persons since the 1970's, when it was between 50,000 and 70,000 individuals. "And that was well before the graying of America," said McNulty. "We are trying to develop a national registry."

The Helen Keller Center exists in large part because Bob Smithdas went to Washington, D.C., in 1967 and helped obtain federal funds. He testified that without sight or hearing a person could still achieve great heights - he served as the perfect example. A temporary facility was opened in New Hyde Park in 1969.

At a gala fund-raiser in November, Bob Smithdas was presented with a lifetime achievement award. The event marked the 25th anniversary of the opening of the Helen Keller National Center at its current site in Sands Point. The presenter was Barbara Walters, who first interviewed Bob Smithdas more than 25 years ago and describes him as "the most memorable person I have ever interviewed." Walters interviewed the couple together in 1998.

In the November 2001 issue of Ladies Home Journal, Walters named Michelle Smithdas as "the most empowering woman" she's ever met. "I never knew I was married to such a powerful woman," Bob Smithdas said, laughing, as he offered his arm to Michelle and the couple walked out together into the radiant glow of a warm, autumn afternoon. They couldn't see it, but, no matter, they seemed to have eyes only for each other.

Ellen Mitchell is a freelance writer. She wishes to acknowledge the kind assistance of Sue Ruzenski, director of the Direct Service Program at the Helen Keller Center, and John Mascia, director of Field Services, for their interpretive expertise.

CAUGHT IN QUAGMIRE

By Alexandra Rockey Fleming

(Reprinted from The Washington Times, Washington, D.C.)

The fantasy of winning the lottery differs in everyone. Some people might blow their earnings on a vacation home with an ocean view. Some might begin a classic car collection. Others might quit work and go fishing - forever.

Springfield mother, Marcia Praeger, has another idea of how she would spend her earnings. "It would all go for Erin to set her up for life - and those like her," Mrs. Praeger says.

At the moment, Erin Praeger, 24, is not set up for life. Indeed, it seems Mrs. Praeger and her husband, Dirck, a retired Marine, will need to hit the jackpot to ensure that their daughter, who is deaf and blind, receives the specialized care they believe she needs. Like parents of disabled adults everywhere, the Praegers for years have provided inexhaustible physical, emotional and financial support to their daughter. It is their wish, especially as they glimpse their own mortality, to see that she receives support and care in a group home environment in which she can thrive for the rest of her life.

The Praegers, like thousands of Virginia families of developmentally disabled adults and thousands more nationwide, are caught in a quagmire of long-term funding and staffing limitations that have left them anxious and frustrated.

"The most important service - residential service, which is a group home or a supervised apartment - is not available for Erin because of lack of funding," says Mr. Praeger, who works as a civilian systems engineer. "She's eligible for it, like everyone else on the waiting list, but because of a lack of government funding, she can't get it."

Mr. Praeger estimates that an appropriate group home setting and treatment for Miss Praeger would cost from $4,000 to $5,000 per month. Generally, community settings such as group homes are less expensive than institutional placement.

The Praegers are not unusual in desiring community-based care for their daughter, says Jeannie Cummins, director of advocacy and programs for the Arc of Northern Virginia, a nonprofit advocacy organization for the disabled. "Most families today want to see their son or daughter be as involved and included in their community as possible," she says. "There are very few people who would choose to live in an institution. Some people need that level of care - I won't deny that - but very few would choose to spend their lives in one."

To provide Miss Praeger with this community-based care, says Mr. Praeger, "we could liquidate all of our assets and take everything and throw it at Erin, but then we eventually would become wards of the state ourselves. It's really a tough nut." Says Mrs. Praeger: "Erin deserves a life and some happiness. She deserves a chance to be on her own."

Americans haven't always believed that people like Erin should get any chances, says David Braddock, executive director of the Coleman Institute for Cognitive Disabilities at the University of Colorado School of Medicine. Mr. Braddock has been involved with the developmentally disabled for 33 years and has testified before Congress on the current problems within the care delivery system.

"The U.S. like so many other developing nations, ignored people with developmental disabilities as if they didn't exist," he says. "We're engaged now in a period of recognition of the rights of people with developmental disabilities and our responsibilities toward them. We're in the process of catching up with those generations of neglect, and so it shouldn't be surprising that we've fallen behind. The modern era didn't occur until the last 20 years.

Mr. Braddock points to several elements that influence the current demand for services. One is the graying of America due, in part, to increased longevity and the size of the baby-boom generation. Most people with developmental disabilities live with family caregivers, he explains, so formal living arrangements must be found when these caregivers get too old to shoulder the demands, both physical and psychological, of providing for a person with disabilities.

The second force is the increased longevity of people with developmental disabilities. For example, he says, 9 years was the average age at death for someone with Down syndrome during the 1920's. The average age at death rose to 30.5 years in the 1960's and 55.8 years in 1993. With continued sophistication in medical care, many people with disabilities can expect to have a life span equal to the general population.

Like the general population, people with disabilities require basic services, including education. All children in this country are eligible to be educated within the public school system. Once they "age out" of the system at 22, young adults with developmental disabilities can apply for county funding for day support services such as vocational training and recreation. But applying is not the same as receiving, says Tamar Heller, head of the Department of Disability and Human Development at the University of Illinois at Chicago. "Funding for family supports are woefully inadequate," Ms. Heller says. "In fact, there are no mandated services after public school."

More than 70,000 developmentally disabled people nationwide are on a waiting list for some kind of day support, she says. In that regard, Miss Praeger was one of the lucky ones. Virginia through the Department of the Visually Handicapped, paid from $46,000 to $50,000 to send the young woman through 18 months of specialized care at the Helen Keller National Center, a vocational and rehabilitation training program for people who are deaf and blind in Sands Point, NY. There she polished her vocational and daily personal care skills. Her program now completed, Miss Praeger returned home to her parents and younger brother - and to an uncertain future.

Miss Praeger needs constant specialized support and services to live comfortably, maintain her independence and realize her potential, her parents say. Without these factors, she will lose whatever edge she has gained at the Helen Keller Center.

The Next Step

Miss Praeger's parents applied for funding for her under Virginia's Medicaid Mental Retardation Waiver program, which allows the state to direct Medicaid funds toward community-based supports such as group homes, independent living training and personal assistance. The federal government matches state contributions to the waiver program. Eligibility is based on the level of assistance a person might need to qualify for long-term Medicaid care.

"Medicaid used to only fund placements in institutions," Ms. Cummins says. "The Medicaid waiver

diverts funding that would be going to institutional placement - and the services would have to cost less."
But names are being added to the waiver eligibility list more quickly than they are removed, she says. Nationally the waiver waiting list is 80,000 names strong. In Virginia, the current number is 1,400.

But even if every person's place were funded, says Ms. Cummins, the problem would not be solved. The final problem, she says, is that the reimbursement rate for service providers under the MR waiver has stayed about the same since the waiver was put in place in 1991. The result? Even a job in fast food may seem more appetizing to many in the employment line.

Officials in Virginia's Department of Medical Assistance Services (DMAS), the state Medicaid agency, are well aware of the problem, says spokeswoman Leah Hamaker, and are taking steps to address it. In recent actions, she says, the department has increased the number of individuals served from 3,100 in 1998 to more than 3,700 in 2000. MR waiver expenditures have increased by 63 percent since Gov. James S. Gilmore III took office.

Last year Gov. Gilmore convened a task force comprising representatives from community service boards, providers, advocates and family members to revise the waiver. The changes, she explains, would include strengthening provisions for quality, examining ways to develop provider networks, add more consumer direction for the services and add the element of freedom of choice of provider. Ms. Hamaker says approval may come this month. "We are working really hard with this new waiver, and we are trying to address everyone's concerns," she says. "We are committed to serving this population."

But that commitment won't remedy Erin Praeger's situation, say her parents. They say they know of a new group home in Staunton, Virginia - about 150 miles away from their home in Springfield - that has been created specifically for people who are deaf-blind.

"This is almost a once-in-a-lifetime

opportunity for Erin - that there is an opening at the time she is coming home from Helen Keller," says her father, a veteran of the Vietnam War who served two tours of duty. "But she has zip, zero, no chance. The people want her there, but she's not funded."

"The bottom line is that all these parents want to be parents," Ms. Cummins says. "They want to celebrate their children's achievements and see their children through the rites of passage like we all do. It's just that they want to be able to wear the parent hat like all parents do."

She continues: "They don't want to be their child's attorney, nurse, case manager and therapist for the rest of their lives. It's neither good for the parent nor for the child."

EMPLOYEE SPOTLIGHT: DEBBIE SOMMER

(Reprinted from HORIZONS, newsletter of The Seattle Lighthouse for the Blind, Seattle, WA)

Debbie on the job!

"One of our favorite family activities was going out on Christmas Eve and looking at the Christmas lights," recalls Debbie Sommer, a sixteen-year Seattle Lighthouse employee. "One Christmas when I was about thirteen years old, my family was gathering together to go out and look at the lights," continues Debbie. "When I tried to walk up to the house I missed the stairs completely in the dark. My sister had to help me to the house. That's when we realized I was suffering from night-blindness."

Born totally deaf, Debbie later learned she has a genetic condition called Usher syndrome. "When I was about two years old, my parents realized there was something wrong with my hearing," Debbie explains. "At that time we moved from Nebraska to Colorado so I could be seen by an audiologist there. He had lots of experience with deafness. He also told my parents he thought I might be mentally retarded, but they told him there was no way. They knew their daughter."

When Debbie was about five years old, her parents enrolled her in a public school where instruction centered on teaching deaf children to speak. "This was an oral school," Debbie recounts. "I didn't learn sign language. It was very difficult to communicate with my family, and it was extremely difficult to learn things like math and English." Then, at about age thirteen, Debbie transferred to a school for the Deaf. "I started learning American Sign Language, and it opened up a whole new world for me," she says. "It was about this time I started suffering from night-blindness and had my Christmas Eve episode, but we didn't really know what was going on."

Finally, at age twenty-one, Debbie visited a center for the blind and spoke to someone familiar with Usher syndrome. People with this genetic condition are typically born deaf, losing their sight over time due to retinitis pigmentosa. "The person explained what Ushers is and what it would mean for my life. They told me I would eventually lose my sight and would need to learn blindness skills like Braille, and how to do tactile sign language so I could feel the hands of the person signing to me. It was extremely depressing at first, and I also suffered from lots of denial. Now I have come to accept that this is my life and I must live the life I have without being angry."

After learning the facts about Usher

syndrome, Debbie traveled to the Helen Keller National Center in New York for a year of training. "I learned everything from mobility training, to daily living skills like sewing, and communication. I also had my first opportunity to socialize with other adults who had Usher syndrome."

Following her year of training, Debbie returned to Colorado, but found no suitable employment opportunities. Suffering through a few unsatisfactory forays into the world of work in Colorado, Debbie next found herself in Seattle. "I went to Seattle to attend the annual conference of the American Association of the Deaf-Blind," Debbie says. "Part of the conference was a tour of the Lighthouse. I had heard about the

Lighthouse for years, and now had a chance to visit. Shortly after returning home to Colorado I thought to myself, why not move to Seattle?"

Packing up and moving to the Northwest, Debbie did indeed find employment at the Seattle Lighthouse. "I've worked in many different areas of the Lighthouse," she reports, "from putting together hose assemblies for big trucks, to the Boeing area, to making paper trimmers, file folders, binders and easels."

In addition to employment, Debbie has discovered the wonders of computer technology at the Lighthouse. "I was hearing about people using e-mail," she says. "People communicating with friends and family, and making new friends all over the world. But there was no way to use braille with the computer. This inaccessibility of such a fantastic technology was very frustrating.

Then, a few years later, I heard that the Lighthouse was getting some Braille equipment that could be used with computers for e-mail. I decided to be assertive and get started as soon as I could."

Debbie enrolled in the Lighthouse's Education and Training Programs. "I was so far behind at first. It took me a long while to just learn the basics. We did not have any deaf-blind instructors at that time, so everything was done with interpreters," she recalls.

Eventually, Debbie mastered e-mail and Microsoft Word. "At Christmas time I can send messages and cards to my family and friends!" she exclaims. "Since English is not my first language - ASL is - my English is not that good. But that doesn't really matter. It's the communication that counts."

Last summer Debbie was enrolled in another Lighthouse Education and Training course with a deaf-blind instructor to learn how to access the World Wide Web. "I'm so excited about learning more and more about computers, about e-mail, and about the Web. It's extremely liberating for me as a deaf-blind person to have these tools for communication and access to information," Debbie concludes.

ESSAY: A DAUGHTER'S VIEWPOINT

By Rachel Jacobs

When my mother told me "I don't know what I'll do when you go to college" on one of our frequent walks together, I did not completely comprehend what she was trying to tell me. Being her oldest child, I understand she will miss me when I leave, but at that moment the full meaning of what she said did not occur to me.

Then one day, as my mom and I shopped together in the mall, I realized what she meant.

We walked past some clothing stores and,as we passed each window, we stopped and I described the outfits hanging on the mannequins. I repeated myself several times since my mom is hearing impaired. As we continued strolling down the mall's breezeway, I noticed several people sitting on benches and glaring at my mother. I checked over her clothes to make sure her zipper was not undone or her shirt unbuttoned, but her outfit looked fine.

I noticed then that the people were staring at Lotus, my mom's guide dog. It never occurred to me before how unique my mom is and how much I help her.

Suffering from a genetic disease called Usher syndrome, my mother has progressively lost her sight and hearing. Now, at age forty-eight, she is almost totally blind, only seeing hints of shadows and hearing with the help of two hearing aids. Even then communicating can be difficult at times.

Despite her disabilities, my mother continues to live her life the way anyone else would, except for a few minor adjustments here and there. However, no matter how much my mother tries to live a fairly normal life, she faces daily challenges created by her disabilities.

These challenges pose obstacles for me, too. I am aware that my life at home is much different than most teenagers' lives. I pick my mother up from work almost every day after school and help her cook dinner, set the table or do the dishes. My mother needs help and for my whole life I have been accustomed to helping her without complaining much.

There are other challenges which arise in my role as a daughter of a deaf-blind woman. I recognize my duty to keep my mother safe whenever I am guiding her. Crossing streets, walking in airport terminals, shopping in the grocery store - all of these events pose dangers for my mom. So, when accompanying my mother, I take her safety and life into my hands and have done so for quite a number of years. With this added responsibility, my mom rewards me with her guaranteed trust.

Yet my relationship with my mother is equalized. I do things for her and she does things for me. As a mother she has taught me many important lessons. There were times in my life when I wanted to give up.

In fifth and sixth grade I was having a lot of trouble in math and science. In eighth grade, my grandmother died. There are many other instances when I felt like dropping everything, locking myself in my room, and hiding under the secure blankets of my bed. But my mother flung those comforting sheets away from me, forcing me to face my problems and figure out how to solve them. She taught me never to give up by never giving up herself.

My mother still works as an active veterinarian/professor at the University of Georgia. She has received many teaching awards, including the highest in the whole university, for her outstanding capabilities as a teacher. The zest she possesses in everything she does inspires the people who know her. I am fortunate to be a beneficiary of her teachings and a recipient of her enthusiasm.

Sometimes I forget that my mother is blind and deaf because of her involvement in activities. In pictures I've taken, someone would never guess my mom is blind because of the settings.

For example, there are photographs where she is standing on skis on the slopes of Norway and sitting on a kayak in Panama, Central America. The only hint that gives away my mom's disabilities is her bright orange ski bib, which reads "DEAF-BLIND

SKIER."

I embrace my mother's disabilities as a way to mature more quickly and be independent. I also have come to realize that my mother is not the only person who needs help, so with my experience of assisting her in obstacles I have reached out to the community and offered myself for aid.

Many people ask me how I deal with a deaf-blind mom and tackle the depressing emotions attached to her disease. I never have an answer to give to them because they couldn't understand.

Her disabilities draw us together to support each other when we confront difficult problems. Hers tend to be obstacles dealing with her disabilities and mine usually range from school to friends. Nonetheless, I firmly believe that my mother and I are closer than most because we have to face her handicaps together and in doing so, we have become best friends.

DEAF AND BLIND MAN JET-SKIS INTO LONDON

(From the News Room of the BBC, England)

A deaf and blind man, traveling 300 miles by land and sea, has completed his journey on a jet ski.

Graham Hicks, 40, from Peterborough, Cambridgeshire, was met by well wishers when he finished his trip at Blackfriars in central London on the River Thames. Jon Hartland, retails operation director for Sainsbury's, challenged Mr Hicks to travel in a unique way from Peterborough to London after he had walked the distance for charity in June.

Relishing the challenge, Mr Hicks, who is nicknamed "G-Force" and is challenges co-ordinator for the charity Deafblind UK, rode a tandem bicycle from the company's head office in Peterborough on 11 August to Hunstanton, Norfolk.

The next day he set off for London on his jet ski, which he takes full control of, with a hearing-sighted pillion rider to navigate using a touch-based signaling system. The walk earned the charity 33,000 pounds and Mr Hartland added another

7,000 pounds for Mr Hick's jet ski efforts.

Mr Hartland said: "I never expected him to do something as spectacular as making his way by tandem and jet ski, but that's Graham for you. "He's fired with adrenalin and he's determined to prove to the world that deafblind people can achieve as much if not more than able-bodied people, given the opportunity."

Mr Hicks, who holds two Guinness World Records for jet-skiing and quadbiking, said: "If any other company wants to set me a challenge, then I'm open to suggestions."

DEAF-BLIND COMMUNITY ACCESS NETWORK PROGRAM TO BEGIN IN MASSACHUSETTS

Deaf-Blind adults residing in Massachusetts are about to have the support of a new program designed to enhance mobility, communication, and access to a wide variety of daily living activities outside the home.

The new program, funded for the first time in FY '01 by an allocation of $350,000 from the Massachusetts legislature, is the result of extensive advocacy efforts conducted by the Deaf-Blind Interpreter Allies (DBIA). Great commendations go to the members of DBIA, and to countless supporters from all across the state whose letters, calls, and testimony made this new program possible.

The contract to create this statewide Deaf-Blind Community Access Network (DBCAN) program has been awarded to D.E.A.F., Inc., in Allston, Massachusetts, through a competitive process overseen by the Massachusetts Commission for the Blind in collaboration with the Massachusetts Commission for the Deaf and Hard of Hearing.

The new program is targeted to recruiting, training, and supervising DBCAN Providers who will be hired to assist Deaf-Blind adults by providing sighted guide and communication assistance.

The DBCAN Program was scheduled to be operating and fully staffed before June 2001. D.E.A.F., Inc. has contracted with a team of interim consultants to implement start-up procedures, recruit staff, and conduct community outreach. Jacqueline Woodside, LICSW has been appointed as Interim Director to oversee the work of the start-up team.

For more information on the DBCAN Program, readers may contact D.E.A.F., Inc. at 215 Brighton Avenue, Allston, MA 02134. E-mail may be sent to DBCANProject@aol.com

DEAFBLIND INTERPRETER ALLIES DEAFBLIND COMMUNITY ACCESS NETWORK (DBCAN)

Introduction

Of approximately 600 Deafblind individuals identified in a Massachusetts study in 1987, an estimated 100 or more adults have been consistently unserved or under-served. These are Deafblind adults and Deaf adults with deteriorating visual conditions that live and work in the Commonwealth. They are otherwise physically and cognitively able. They desire to live independently, to do meaningful, satisfying work, to study, to play, and to contribute to the community.

No single depiction can adequately capture the range of experiences of Deafblind people. Some are hard-of-hearing and partially sighted, and others live with total deafness and blindness. Some experience tunnel vision, whereas others cannot see at night. Some are born deaf or hard-of-hearing and experience progressive loss of sight over the course of their lives. A smaller number are born deaf and blind. Some with limited vision may be able to see American Sign Language at close range. Others understand language tactually. Some are mobile using a cane or guide dog to navigate public transportation. Many are housebound.

The challenges of communication and mobility can keep Deafblind adults at home, isolated. Activities of daily living-banking, shopping, correspondence, exercise - activities simple for sighted, hearing individuals, can become mammoth or even impossible chores without the accompaniment of sighted guides who can communicate using sign language in forms accessible to Deafblind people.

All of us at one time or another in our lives, due to illness, accident, or aging, will require the assistance of others to help with daily life activities outside the home. At times, we generally turn to friend or family for help. For the Deafblind population, this is a day-in day-out, week-after-week, year-after-year challenge requiring help from specially trained individuals who can communicate fluently in sign language and safely guide a Deafblind person out in the community. "Volunteer" assistance cannot reliably provide Deafblind people equal access to the community.

The Deafblind Community Access

Network (DBCAN) has as its goal to provide equal access to community life for independent Deafblind citizens so they can enjoy and improve the quality of their lives. A formal organized program, the DBCAN will coordinate assistance to Deafblind people in some of their day-to-day life activities outside the home. The program will seek out and identify Deafblind adults who would benefit from the program and recruit, train, and supervise DBCAN providers.

Deafblind consumers have been and will continue to play a central roll in planning and future implementation and evaluation of the DBCAN Program.

Definitions

DBCAN Providers: DBCAN Providers

assist Deafblind adults in leading fully active lives. They provide basic communication assistance and sighted guide services in activities of independent living such as: Errands (barber/salon, dry cleaners, post office, library); shopping; banking; doctors appointments; reading; correspondence; exercise; fitness programs; getting to and negotiating the airport; transportation assistance (public transportation, The RIDE); community educational programs; recreational and cultural events; apartment hunting; visiting and hobbies.

DBCAN Providers will: Have sufficient language ability to communicate in ASL, English, tactile and close vision communication to provide communication access; have sighted guiding skills; have good "people" skills; maintain confidentiality; record and report hours of service; be screened; be trained; be paid.

DBCAN Providers will NOT: Provide rides only; do chores such as housecleaning; provide personal care services such as bathing, cooking, etc.; move furniture; interpret; teach; make decisions for the Deafblind individual.

Consumer Eligibility and Responsibilities

DBCAN consumers will be Deafblind adults living independently in the community, certified deaf or hard-of-hearing by MCDHH

(Massachusetts Commission for the Deaf and Hard of Hearing) or MRC (Massachusetts Rehabilitation Commission) and legally blind or having a diagnosed deteriorating visual condition.

Deafblind consumers will: Be trained in role and function of DBCAN Providers (including assertiveness training); record and report hours; provide feedback to coordinator for purposes of evaluation and to DBCAN Providers to foster improvement; be responsible for expenses such as gas money, parking fees, bus fare, and admission fees.

Qualified Vendor

Communication is the core issue in providing quality services to Deafblind people. A qualified vendor for DBCAN services must:

*Insure that all information, including visual information, is provided in the desired communication mode of the person being served.

*Hire staff who possess a complimentary set of language and communication skills to meet the broadest possible spectrum of language and communication needs.

*Provide qualified interpreters for larger meetings or when the communication needs of the Deafblind person cannot be met by agency staff.

*Insure that all services are provided with the fullest possible participation of the Deafblind individual.

*Demonstrate success in providing

services to Deafblind adults.

*Have the capability to meet statewide needs.

*Have proven fiscal management capability and experience.

*Demonstrate a knowledge of Deafblind people and a commitment to obtaining and using the advice of local Deafblind consumers and to hiring of qualified people who are Deaf, hard-of-hearing and Deafblind to provide services under this program.

*Be a not-for-profit agency that provides an array of independent living services or other related services to people who are Deaf, hard-of-hearing, and Deafblind; and whose governing board memberships includes Deafblind Community representation.

Program Staffing

Three roles for staff are required.

Coordinator: Responsible for program oversight, budget management; liaison with state funding agency, program-related policy development with input from other staff and the community; record-keeping and reporting; scheduling services; program evaluation.

Outreach Specialist: Identify and recruit Deafblind consumers. Recruit, conduct background checks, and select DBCAN Providers. Will provide backup DBCAN Provider services as needed.

Trainer: Responsible for training Deafblind consumers in assertiveness, tracking of hours of service, and appropriate support and respect of volunteers, training and supervision of DBCAN providers; assisting in scheduling.

SANDS POINT CENTER INTRODUCES DEAF-BLIND TO A WIDER WORLD

By Laurie Nadel.

(Reprinted from the New York Times)

Michelle Smithdas has been through hell.

Not that you would notice. A petite, trim woman with short brown hair and blue-gray eyes, Ms. Smithdas, 53, will tell you, "Yes, I am happy," and her rich, alto voice is punctuated by riffs of laughter.

But it was not always so for Ms. Smithdas, 53, of Port Washington. Hearing-impaired since her birth, she became profoundly deaf at age 16. When she was 23, a snowmobile accident threw her world into darkness. "I went into a coma at first," she said. "Then, after I came out of that, all of a sudden, things went out. Of course, the first thing I thought was that the light bulb burned out. I flicked the switch up and down. I saw no lights and began to panic. At first, I wasn't sure I would go on. I even thought about committing suicide."

But she regrouped and resumed her studies, graduating in 1971 from

Gallaudet University, the famed school for people who are deaf, and earning a Master's Degree in Education of the Blind and Visually Impaired from Columbia University in 1989.

In February 1972, she arrived as a student at the Helen Keller National Center for Deaf-Blind Youths and Adults, which was at that time operating out of a former spice factory off Jericho Turnpike in New Hyde Park, New York. In 1974, Ms. Smithdas began teaching Braille, sign language and other communications skills to other people who are deaf-blind at the Center, which moved to its campus in Sands Point, on land owned by the

Guggenheim family, in 1976. It celebrated its 25th anniversary in November, 2001.

"Because I am a former student, I feel I can honestly share my experiences with students who are facing the problems and limitations of being both deaf and blind," she explained one Friday morning as she sat in the office of Sue Ruzenski, a Stony Brook resident and a director at the Center.

Ms. Ruzenski, 45, who can hear and see, was spelling a reporter's questions into the palm of Ms. Smithdas' hand. As she recognized each word or phrase, Ms. Smithdas nodded to indicate that she understood. Her mobile face was a montage of shifting expressions, from frowns of concentration to radiant smiles.

Bob and Michelle

"Yes, I am told I have a beautiful smile," she said as her husband of 26 years, Robert Smithdas, walked to a place behind her chair, and placed his hands on his wife's shoulders. She took his left hand and began to spell words into his palm while he stroked her cheek with his other hand. "Our hands convey a lot of emotions," she said. "I know when Bob is upset because his fingers will spell rapidly into my palm."

Taking a seat next to his wife, Mr. Smithdas, 76, also a director at the Center, explained that he lost his own sight and hearing after he came down with spinal meningitis at age 5. "I was totally blind and 95 percent deaf," he explained. "As I grew up, I couldn't hear myself speak, nor could I hear others speak."

At age 16 he entered the Perkins School for the Blind in Watertown, Massachusetts, where his teachers helped him to control the pitch and tone of his voice. In 1946 he received a fellowship to St. John's University in New York City, and in 1950, Mr. Smithdas became the first deaf-blind person to graduate from college since Helen Keller graduated from Radcliffe in 1904. He went on to New York University, and in 1953 he became the first deaf-blind person ever to be awarded a master's.

He does not count that as his most important achievement. "My biggest accomplishment is getting this place started," he said in a breathy baritone. Mr. Smithdas's face, unlike his wife's, was as sturdy and expressionless as a Mount Rushmore president.

Mr. Smithdas conceded that he, too, has had periods of despair. "At first, everyone who has a disability gets angry and depressed and feels that no one cares," he said, slowly and carefully enunciating each consonant. "But over time, you learn to have patience."

A one-hour experiment, wearing earplugs that muffle - but do not block - all sounds, and goggles that simulate glaucoma conducted under the supervision of Maura Platz, supervisor of the Center's Independent Living Department, provided a better understanding of the obstacles which people who are deaf-blind encounter while performing basic everyday tasks. Without sight and with only minimal sound, it soon became obvious why the world through which a deaf-blind person navigates is practically incomprehensible to anyone who can hear and see.

It is not so much the silence or

the darkness that make it hard to function; rather, it's the disorienting inability to gauge space and distances beyond one's reach. Walking each step becomes a strategic exercise in which one foot carefully feels the ground while the other is gingerly lifted and lowered.

With only minimal visual or auditory cues to provide a guide to the relative distance of an object or another person's presence, a deaf-blind person moves through what feels like a thick, dark tunnel. A dim auditory awareness that other people and objects are nearby - something denied to the profoundly deaf - is confirmed through touch and smell, senses that, as Ms.

Smithdas explained, "learn to work together."

Making a grilled cheese sandwich in the kitchen of the Center took almost the entire hour. It became clear that basic tasks such as planning menus, shopping, cleaning up, doing laundry, identifying clothing and negotiating transportation need to be taught with sensitivity and a focus on personal safety. That's where the Center comes in.

It was established by Congress in 1968 to teach people who are deaf-blind the skills to take care of themselves and function in society. In addition to the national headquarters in Sands Point, the

Center operates 10 regional offices and gives annual grants to 43 state and private agencies that help deaf-blind people.

"As a society, we owe it to them to provide them with opportunities to succeed," said Joseph McNulty, 54, a Long Beach resident and the Center's executive director. "Every day, they show us that given quality education, rehabilitation and support, they can have great successes."

Among those successes, Mr. McNulty said, is the Center's training of deaf-blind instructors and administrators. "Twenty-five years ago, we had only Bob and Michelle Smithdas," he said. "Now we have 10 deaf-blind people working in important positions, including two regional representatives and our technology supervisor."

"Some people come for eight weeks and others stay for a year," said Ms. Platz, a 31-year-old Port Washington resident. She pointed to the kitchen drawers labeled in large print and Braille. "People who have limited vision can read the large print. For those who are profoundly deaf and completely blind, we glue utensils, bowls, soup cans and other samples onto the doors of the cabinets so people will know what's inside. We also create communication cards by pasting wood block letters or small objects onto laminated 5 by 7 inch index cards for those who have not yet learned Braille, fingerspelling or sign language."

Thirty-eight people are currently enrolled in the program at Sands Point. In the course of a year, about 100 deaf-blind people from around the country and overseas come through the campus, and there's a one-year waiting list. Those who are sent here for training make up a bare fraction of the total population of 70,000 deaf-blind people in the United States.

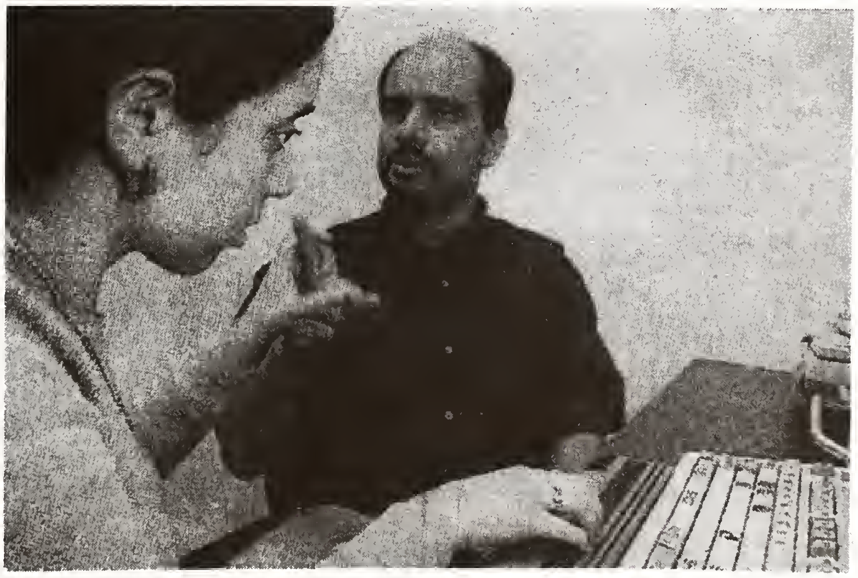
The Center receives $8.5 million a year from the federal government, about 80 percent of its $11 million annual operating budget. Most of the remainder comes from grants and charitable contributions.

The real estate mogul, Leona Helmsley, has made a $525,000 contribution to a new conference center and auditorium that are scheduled to open in January, 2002.

A sliver of additional income comes from fees for tuition, room and board. "We charge each state for each participant," Mr. McNulty said. "The money comes from the states' rehabilitation agencies. Although we charge $27,000 per person for one year of residency and training, the true cost to us is $100,000 a year." That sum includes training on state-of-the-art communications technology which gives deaf-blind people access to the world.

Anindya Bhattacharyya (Bapin), 30, was seated in front of a personal computer with a monitor and two keyboards, one standard and one that displays "refreshable" Braille by pushing up formations of electronic pins to form Braille letters. Within seconds of his typing a message on the standard keyboard, his words flashed on the monitor of a matching system at an adjoining desk. A response was sent, and Bapin, who is completely blind and profoundly deaf, read the incoming words on the refreshable Braille keyboard.

As technology supervisor at the Center, Bapin, who is originally from India and who now lives in East Meadow, supervises a staff of three, teaching students how to use computers with Braille displays and adaptive technologies. He has been working with the Department of Education, the American Association of the Deaf-Blind and several private companies to develop new models of Braille communicators and printers.



Bapin works with former student, Catalina Acevedo

"The equipment is very expensive," he typed. "This system cost around $8,000. There is only a small demand for it, so companies are not developing new models."

This technology is opening up new worlds to people who are deaf-blind. Not only are they able to get jobs in such fields as data processing, transcription and computer programming, they can now access the Internet.

"What prevents deaf-blind people from participating and working is that they don't have access to information," Mr. McNulty said. "If you are deaf-blind, learning how to use this technology can open up the world for you."

But for regular conversation, signing still seems to be the preferred means of communication. Turning away from his keyboard, Bapin extended his left hand to Lewis Merkin, an interpreter, who spelled a reporter's words into Bapin’s palm. Bapin explained that he was born deaf in a town in India but did not become blind until he was 9.

"I lost the sight in my right eye when I was 6 because someone threw soil into that eye and my retina became detached," he said. "When I was 9, I was chosen to be captain of my rugby team. Someone who was jealous threw ash into my eyes. The doctors tried to save my vision but they could not. I could no longer play rugby and I was very angry," he continued. "This was a humiliating experience. I had friendships before. Now I did not know how to communicate, nor could people communicate with me. People did not have patience with palm reading. I got depressed. Coming to America changed my life."

Maricar Marquez, 30, is a senior instructor at the Center. "My job is to evaluate students' independent living skills so that we can develop a personal training program for each one," she explained in sign language. Legally blind and deaf since her birth in the Philippines, Ms. Marquez moved to Canada with her family as a child and came to the United States for graduate work at Gallaudet University, where she received a Masters' in Communication Administration before coming to work in Sands Point.

A resident of Port Washington, where she lives in an apartment with a roommate who has sight and hearing, Ms. Marquez said she enjoys her independence and likes to challenge herself. An accomplished athlete, Ms. Marquez has skydived, spelunked, and gone rock climbing.

In 1998, she completed the 11th annual Seacrest-Tobay Triathlon in one hour, 51 minutes, 46 seconds, placing in the middle ranks of 1,100 contestants. Four interpreters from the Helen Keller National Center swam, biked, and ran with her communicating with taps and touches to help her stay on course.

Nonetheless, she said, her biggest challenge remained "how to educate people about what it means to be deaf-blind."

LIFE DEVOTED TO DEAF-BLIND COMMUNITY

By Ann Rodgers-Melnick

(Reprinted from the Post-Gazette, Pittsburgh, PA)

With her flair for public relations, Karen Ahearn McGann might have thrived in corporate America, but she devoted her life to making deaf people at home in the Catholic Church. The 47-year-old Brookline, Pennsylvania, resident died in August 2001, from Hodgkin's disease, leaving a legacy of support programs and strong faith.

"She was a woman who was completely dedicated to the mission of including all people with disabilities, but particularly our deaf and deaf-blind people, into the fullness of the church. And she succeeded brilliantly," said Grace Harding, director of the Catholic Diocese of Pittsburgh's Department for Persons with Disabilities.

"Karen created joy wherever she went. As a woman of faith, all the joy radiated from Jesus Christ. Everything she did was for the Lord."

That faith was an inheritance from her parents, Lee and the late Marilyn Ahearn. But it was her little brother, Jimmy, who influenced her life's mission. She was 12 when the 17-month-old lost his hearing due to spinal meningitis. With the rest of the family, she learned sign language and became immersed in deaf culture.

During the golden years of the Pittsburgh Steelers, she worked as a personal assistant to star running back Rocky Bleier, developing a flair for public relations. Her ministry began informally when a priest asked her to teach religious education to a deaf child.

In 1983, the diocese hired her as its "pastoral worker for the deaf." Eventually she became director of the Catholic Office for Deaf Persons. As such, she oversaw an after-school program of Catholic education for Catholic students at the Western Pennsylvania School for the Deaf.

"She was a warm, caring person who went out of her way to help anyone who she came in contact with. It didn't matter if they were Catholic or not," said Gregg Bowers, dean of students at the school.

Mrs. McGann ran a program to enable each parish to have a trained volunteer advocate for parishioners with disabilities. She also worked with Opening Doors, in which volunteers with disabilities spoke at parochial schools and religious education classes.

She lobbied the diocese to include closed captioning in all of its video programming, including Bishop Donald Wuerl's television show, "The Teaching of Christ." She made sure that all diocesan events offered interpretation for the deaf, and she recruited volunteers and interpreters for the deaf community inside and outside the church. She received numerous awards for her service to the deaf and deaf-blind communities.

In 1994, St. Justin on Mount Washington was designated a bilingual parish for deaf Catholics, and Mrs. McGann became a pillar of parish life. Of the 500 people who worship there on Sundays, about one-third are deaf.

The pastor, the Rev. Walter Rydzon, relied on her as a guide to deaf culture. During his first wedding in sign language, he was rattled when the congregation kept breaking into laughter. During the passing of the peace, Mrs. McGann gently told him that, instead of the sign for "marriage" he had been making the sign for "hamburger."

She authored a book of photographs called "My Church." It documented the faith of a family of deaf parishioners through the eyes of their young daughter.

Mrs. McGann met the love of her life at a picnic for deaf people. Richard McGann had been born deaf and was losing his eyesight due to Ushers syndrome. But he shared her deep faith and relentlessly optimistic outlook. They were married in 1985 by then-Bishop Anthony Bevilacqua of Pittsburgh.

Together they started a support group for blind-deaf Catholics and the nation's first Lion's Club chapter for people who are deaf-blind. They founded the Western Pennsylvania Association of the Deaf-Blind.

"She saw him as a gift, and he saw her as a gift," said Mrs. McGann's sister, Mary Ann Ahearn.

Mrs. McGann was diagnosed with

Hodgkin's disease more than seven years ago. Doctors were initially hopeful she'd be cured. But when it was apparent that was not to be, "she said that her goal was to be the happiest dying person she knew," said Rydzon.

Although she suffered a great deal, she never complained, her friends said. Last fall, when she was very weak, she eagerly volunteered to do all of the publicity for a special Holy Year Mass, Harding said. "She loved putting together brochures, and she handled all of the mailings. It was life-giving for her," Harding said.

By the end of the year it was difficult to breathe, but she came each week to teach religious education to deaf Catholic children, Bowers said.

"She never talked about herself or her problems. She wasn't looking for any sympathy or attention. She was selfless," he said.

In January her heart began to give out, and her doctors told her to quit working. So she began a ministry of prayer from her home. People throughout the diocese wrote or e-mailed prayer requests to her, and she prayed for them faithfully from her sickbed.

On Aug. 5, St. Justin held a special Mass in her honor, which she attended in a wheelchair, with fans blowing over a bucket of ice to keep her cool on the sweltering day. She had helped to teach Rydzon that deaf culture is very blunt, so he began his homily by telling the packed assembly that, "This is not a funeral." He could see jaws drop among the hearing people, who undoubtedly thought him tactless, he said. But when he looked at Mrs. McGann and, "she just laughed. She was howling," he said.

At the end of the Mass she told the assembly that the Mass had been a foretaste of heaven. "I want you to remember how much Jesus loves you," Harding recalled her saying. "That was her last message to us."

The manner in which she faced death was an inspiration to her pastor. "I would say that she let us know that dying is no big thing, that living is the work. I just hope, when my time comes, that I can face it with that same faith," Rydzon said.

On the day after her sister's death,

Mary Ann Ahearn told a mutual friend that she believed her sister was a saint. The friend put it in different terms. "She said that Karen is what God wants all of us to aspire to be, but few of us attain," Ahearn said.

Mrs. Ahearn is survived by her husband, Richard of Brookline; her father, Lee Ahearn of Palm Coast, Fla.; a sister, Mary Ann Ahearn of Palm Coast, Fla.; and a brother, James Ahearn of Mount Washington.

Memorials may be made to the Catholic Deaf Council of St. Justin, 539 Boggs Ave., Pittsburgh 15211.

HERE AND THERE

A new, free catalogue listing instructional books for cooking, knitting, crocheting, tatting and other useful crafts is now available from Horizons for the Blind. Cooks will especially enjoy its new seven-volume book, "Recipes From Boxes, Bottles, Cans and Jars." To order your catalogue, call Horizons for the Blind at: (815) 444-8800, or fax (815) 444-8830. Specify your choice of format: Braille, print, or cassette.

* * * * * * *

"IF YOU ARE BLIND, OR HAVE LOW VISION, HOW WE CAN HELP", is a publication from the Social Security Administration available in print, braille and audiocassette. To order, call (800) 772-1213 and ask for Publication 05-10052 in your preferred format.

* * * * * * * *

The U.S. Department of Justice has released a new technical assistance document for places of lodging. Some of the issues addressed in "GUIDE FOR PLACES OF LODGING: SERVING GUESTS WHO ARE BLIND OR HAVE LOW VISION" include: Check-in and check-out procedures; room keys; room selection; alternate formats; previewing the bill and pay formats. For information call or write to the Department of Justice, Washington, D.C.

* * * * * * * *

A new line of women's clothing with braille and print labels is now available from the Henri Bendel store in New York City. Dee-Dee Dot t-shirts and other items of clothing with washable braille and large-print labels are also available at the website: www.henribendel.com.

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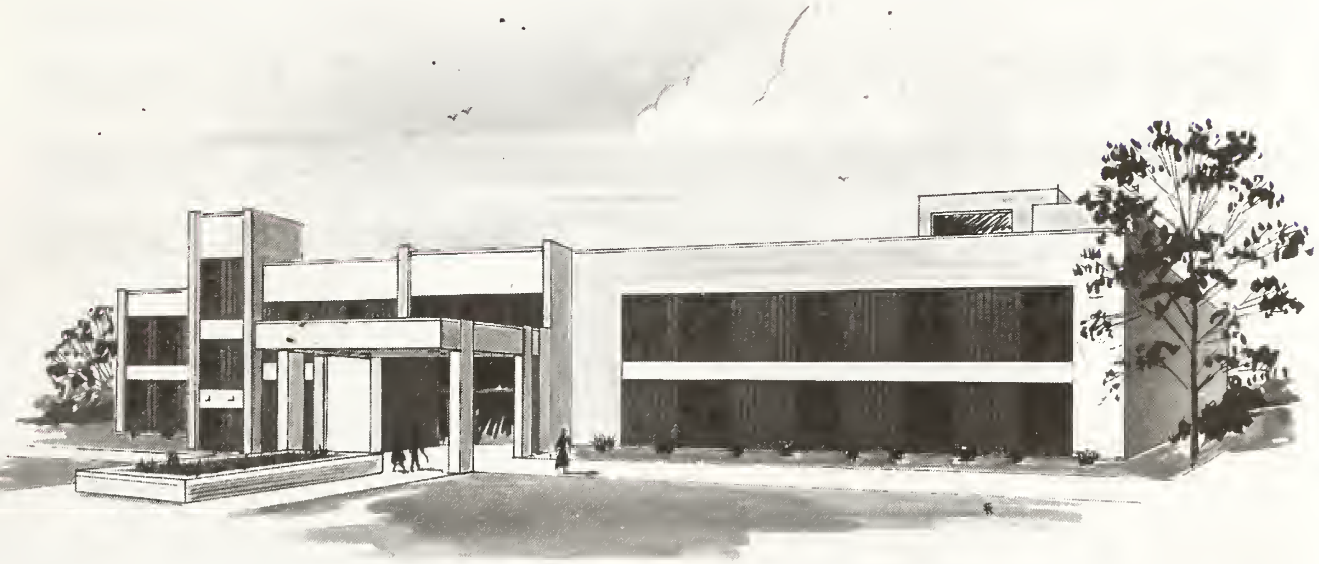

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EDITORIAL: TELEBRAILLE

By Robert J. Smithdas
LHD, Litt.d, LHD

Years ago, back in the early 1980's, I was a member of a small group of eager deaf-blind people invited to California to test the original prototype of TeleBraille, a communication device developed by TeleSensory Systems, Inc., to enable deaf-blind persons to communicate via telephone. It was a historic occasion because it promised to open up new areas of communication that would give deaf-blind users greater freedom of expression and independence as individuals.

Few people are probably aware that

the original concept of what became known as "TeleBraille" had its beginning at the Helen Keller National Center (HKNC) back in the seventies when Frederick Kruger, a neuropsychologist, joined the Center's staff. Charged with developing new methods of signaling and communication based on tactual stimulation, Dr. Kruger began exploring the possibility of transferring messages over phone lines by using an electrically controlled braille cell that produced tactile braille letters one after another.

I still vividly recall the day when Fred came and asked if I would come down to the laboratory to inspect a new project he had just completed. In the laboratory, he handed me a small chunky device topped with a braille cell.

"Now wait," Fred said, "I need a few moments to hook this up. Keep your finger on the cell and tell me what you read."

In less than two minutes the braille cell became warm and began to vibrate gently. Then dots popped up on the top of the cell and I read the word, "hello." I asked "How did you do that?"

"I have the phone receiver in an electronic coupler," Fred answered, showing me how it was set up and a keyboard he was using to spell out the letters transmitted over the phone. I was fascinated. We discussed its potential value as a telephone device and came up with the name, TeleBraille.

But our initial gush of enthusiasm began to ebb over the next few months as we discovered unsuspected obstacles. HKNC did not have facilities for manufacturing such a device, or the necessary funding to hire engineering talent that could perfect it. All HKNC's major funds came from the federal government and a few minor sources, and were dedicated to providing direct services to its students.

Two years later, HKNC made an agreement with TeleSensory Systems to turn over all the basic information and design of the single-cell prototype, which eventually grew into the TeleBraille models I, II, and III. The name TeleBraille was included.

Assistive technology had advanced to the stage where refreshable lines of 20 braille cells were common and TeleBraille used it as a standard. For roughly twenty years the machines provided reliable service with excellent braille output.

Then TeleSensory decided to discontinue manufacturing the machines and sold its braille products division to Blazie Engineering. Though there are still TeleBrailles in continued use, needed parts are less obtainable or not available at all.

Now there are new devices vying for the attention of deaf-blind consumers, each with its own characteristics and useful features, including the Krown Braille TTY outlined in HERE AND THERE.

But TeleBraille was always a good, dependable telecommunication device, and it would be difficult to surpass it. GA to SK!

BEFORE THE MIRACLE

A half-century before Helen Keller, a
deaf-blind girl named Laura
Bridgman was taught to
communicate in English.

By Natalie Angier

(Reprinted from The New York Times
Book Review, May 2001)

Like many girls of the boomer

generation, I was a Helen Keller fanatic. I read books by her and about her. I read books about her teacher, Anne Sullivan. I tied a handkerchief around my eyes, stuffed cotton balls in my ears and tried bumbling around my apartment to see "what it would be like."

Through my Keller phase, I must have come across the name of Laura Bridgman. Anne Sullivan's writings described the deaf and blind girl who preceded Keller in learning language, and who was in fact the true pioneer in stepping out of a sensory deprivation chamber to communicate with the wider world. But the name didn't stick. Maybe that is because the role of disabled super-heroine, like the

American presidency, can be filled by only one person at a time. Or maybe it's because - as Elisabeth Gitter's "Imprisoned Guest" and Ernest Freeberg's "Education of Laura Bridgman" make clear - the story of Laura Bridgman ultimately was one not of triumph but of sadness.

As a girl and young woman, Bridgman was one of the most famous females in the world, her every action celebrated in newspapers, ladies' magazines, the writings of Charles Dickens. By the time she died in 1889, at the age of 59, Gitter writes "she had been almost totally forgotten, eclipsed by the 9-year-old prodigy Helen Keller."

Sadder still than Bridgman's retreat

into obscurity - and she didn't seem to care much about her fame one way or another - was Samuel Howe's gradual disenchantment with her. Howe had been her teacher, her Anne Sullivan, the beloved "Doctor" who pulled her out of her dark, soundless anomie and taught her to speak and read with her fingers, to write, to express her feelings, to know herself and others. But while Sullivan stayed to the end of her life with her demanding and often maddening charge, Howe drifted away from his, leaving Bridgman's care to a long parade of female tutors. He had won his own international reputation as a great social reformer largely as a result of his work with Bridgman, yet eventually he came to view her as something of a failed project.

Paradoxically enough, Howe's sense of failure and disappointment may be the best evidence of his success. For as Laura took her place as a fully realized, three-dimensional individual, entitled to her citizenship in the human race, she had to step off the pedestal Howe had built for her. Once she learned how to express her personality, desires and complaints, she lost her utility to Howe as a virgin canvas on which he could sketch his theories of human nature and human perfectibility. His deaf and blind angel began to seem pedestrian. To top it off, she had the poor taste to get older, changing from an aesthetically appealing child into an angular-faced woman with a decidedly mature body and all its discomforting, musky appetites. Laura Bridgman, Gitter writes, "spoiled his stories simply by growing up." By the end of his life, Howe was saying of the girl he had once lauded for being "as pure and spotless as the petals of a rose" that in fact she sometimes appeared to be as mad as "a wild young witch." Pygmalions: there's no satisfying them.

Gitter, a professor of English at John Jay College of the City University of New York, and Ernest Freeberg, an assistant professor of humanities at Colby-Sawyer College in New Hampshire, give us very different takes on the intertwined stories of

Bridgman and Howe. Gitter emphasizes the emotional relationship between teacher and pupil, while Freeberg focuses on Howe's war against the religious orthodoxy of his time and his attempts to use Laura as cannon fodder. Both books are well written and documented, and though I have a slight preference for Gitter's book - at least the first half of it - neither stands measurably head and shoulders above the other. I can't help feeling sorry for the two authors, who surely felt secure in the uniqueness of their decisions to retell the long-forgotten Bridgman saga. Instead, we now have competing books about a girl who seems considerably duller than her legendary successor, and a man whose personal assessment of himself as a man of "moderate pretensions" and "mediocratic talents" sounds fair enough. Nevertheless, the books jointly present an array of compelling issues, like why we're so hungry for human saints, archetypes and sacrificial lambs; the use of those with disabilities to "teach" the rest of us what life is all about; and the porous boundary between a reformer's zeal and a tyrant's intolerance.

Laura Bridgman was born in December 1829, the third daughter of semiprosperous farmers living in Hanover, New Hampshire. Her mother, Harmony, recalled that Laura was a happy and "more than commonly bright" young child, who by her second birthday was speaking in full sentences and knew some of her letters. But a month later she was struck by scarlet fever, which killed her two older sisters and left her so enfeebled that she spent the next two years in bed. By the time she was able to rise again, doctors realized that she was deaf, blind and almost completely without a sense of smell or taste.

Despite her extreme disabilities, she remained spirited and good-natured, helping her mother with chores like sewing, knitting, braiding, washing potatoes, churning butter, setting the table, ironing the muslin. She had one toy - her father's discarded boot - and one very close friend - an elderly, mentally disabled bachelor from the neighborhood named Asa Tenney. The two often wandered together through the fields and woods, picking wild berries or throwing rocks in the pond. "I loved him as a father," Laura wrote years after his death.

Beyond the silent and ineffable understanding she shared with Tenney, Laura communicated with others through a few mimetic signs for eating and sleeping. When she misbehaved, her mother signaled disapproval by tapping her back or rubbing her hand, while her father, a harsh and impatient man, simply smacked her. Laura might have spent her days in mute and illiterate anonymity if her case hadn't attracted the attention of Samuel Gridley Howe in 1837.

Born in 1801 to a family "on the margins of Boston society," Howe was a man of large if somewhat vague ambitions, "a complex and contradictory figure," Gitter writes, "vain, pugnacious, rigid and arrogant, yet passionately committed to doing good." At Brown University, where his career had been undistinguished, Howe befriended another passionate do-gooder, Horace Mann, and throughout his life traveled with a glittering crowd that included Henry Wadsworth Longfellow, Ralph Waldo Emerson and the woman Howe eventually married, Julia Ward Howe, a writer, suffragist and author of the song "Battle Hymn of the Republic."

Hunger for large adventure after earning a degree from Harvard Medical School, Howe traveled to Greece, where he served as a guerrilla fighter and military surgeon in the Greek revolution against the Turks. Howe returned to Boston in 1831, at a time of intellectual, spiritual and literary awakening called the New England Renaissance. Idealistic "men of letters" argued passionately that it is not enough to do well in life, one must also do good - battle oppression, lift up the poor and disabled, educate the ignorant. Old Calvinist theories of the inevitability of suffering and of original sin were giving way to theories of the "essential beauty and perfectibility of every human being."

Howe caught the reformist fever, and he soon was made director of a new institution devoted to teaching the blind, the first of its kind in America. Convinced that nearly everybody, no matter how seemingly handicapped, is capable of learning and earning a living if only the person is treated as an individual "with distinctive talents and needs," Howe built the school, eventually named the Perkins Institution for the Blind, around a demanding schedule of education, physical exercise and vocational training.

Teaching the merely sightless was

not enough to slake Howe's ambitions, though, and when his friend Harriet Martineau suggested that he attempt what had never been done before - the systematic education of the deaf-blind - Howe leaped at the idea. Beyond the sheer challenge of it, he and his fellow humanists also viewed a deaf-blind person as offering an exceptional window on the genesis of human nature and human knowledge. Then as now, scholars argued over how much of what we are is innate and how much the result of acculturation, experience and sensory input. A person who can neither see nor hear is shut off from two enormous conduits of information about the world. The question was: did the deaf and blind think in the same ways as the sighted and hearing? Did they, in fact, think at all? Or were they trapped in a condition of mental vacuity, a permanent blank slate on which nothing could be written? Howe despised the extremism of the Lockean claim that babies are born into a state of tabula rasa, believing instead that the mind is composed of various "faculties" that, far from being dependent only on external sensations to realize their powers, take an active role in their own maturation. Howe also was an ardent phrenologist, convinced that the faculties of the mind have a physical existence as dozens of separate "organs" of the brain, which in turn are reflected in various bumps on the skull.

Scared, confused and lonely when she arrived at the institute, the 7-year-old Laura Bridgman was to be Howe's test case for the existence of the autonomous mind. On the premise that among the mind's modules is a "linguistic faculty," Freeberg writes, Howe believed that "if he could find a way to speak to her through the lone sense of touch, she would eagerly meet him halfway." Oh, she met him, all right. And though it took some doing, before long she was speaking with the manual alphabet fluently enough to make puns. If one person was said to be "alone" in a room, she asked were two people considered "al-two?"

In showing that Laura could learn and communicate, Freeberg says, Howe felt he had dealt a fatal blow to the notion that "the soul is merely the result of sensation." As word of Laura's accomplishments spread, spectators began flocking to the institute by the thousands to gaze upon the little girl with the green velvet ribbon tied modestly around her vacant eyes and to watch her write, or her fingers dance words into a teacher's palm. Charles Dickens added to the frenzy when he visited Laura in 1842 and waxed lyrical in his "American Notes" over the "fair young creature" whose face was "radiant with intelligence and pleasure," a figure much like his own Little Nell, "a kind of allegory."

But Little Nell, being fiction, could shoulder the burden of allegory; Bridgman, being fact, could not. She began to chafe under the constant pressure to perform, and she would lash out and attack her teachers and the other Perkins students. She hated numbers and avoided her math lessons. She was bright and insatiably curious, but she had her limits. Unlike Keller, she never learned to think deeply or abstractly. And though Howe hoped to inspire in Bridgman a liberal, vaguely deistic religious sentiment much like his own, she eventually ended up as an evangelical Baptist, the very sort of fundamentalism he despised. Her choice may have proved her salvation. Howe abandoned her to wage other campaigns and rescue other souls. Jesus, at least, would never desert her.

KEVIN'S STORY

By Kevin Anderson

My name is Kevin Anderson. I was born May 19, 1961, and grew up in Briane, a small town in the state of Washington. Soon after I began my early schooling, teachers at the school noticed that my speech was not developing normally and suspected I had a problem with my hearing. They told my parents to have my hearing tested.

I began wearing hearing aids when I was six years old and I was sent to a school in Bellingham, Washington, which had a special program for hard-of-hearing students. I was there for three years and then went back to classes in regular public school.

When I was eleven years old, I joined the Boy Scouts and went out camping. That was the beginning when I learned that I couldn't see at night. It was not a good feeling because I loved camping. My eye doctor told me that I should eat more carrots which contain Vitamin B supplements which might help my night blindness.

Eventually I was able to obtain my driver's license, and I drove cars for five years. But in September, 1982, seven doctors told me that I was legally blind.

That was bad news for me and I was very upset. My stepbrother drove me home and I cried all the way. This was not going to be fun for me, I thought. I lost my job in a nursing home for people with special needs because I couldn't see well enough to do the work.

Then I met a regional representative of the Helen Keller National Center (HKNC) named Louis Anderson. He explained the Center's training program and how it could help students who were deaf-blind. In March 1983, I went to the HKNC for training and that was the beginning of a new life for me.

I was afraid when I arrived at HKNC. I had no idea about what would happen and did not know what to expect. I was met by a social worker and a counselor who showed me around the Center, then showed me to my room. As I was walking around I saw other deaf-blind people and I told myself "Hey, they are just like me - I'm not alone!" I felt a lot better! So I started classes and learned how to use a cane to get around, meeting other deaf-blind students and learning sign language.

I was a student at HKNC for about six months and then I got a job there as a clerk. I worked for HKNC for over two years and lived on my own in the community. I really enjoyed it. The Center's staff was great.

Then in January, 1986, I moved to Aberdeen in Washington. I was there for two months but decided to move to Seattle to work at the Lighthouse where many deaf-blind workers were employed. I also found a church for the deaf in the Seattle area and began attending services there in March 1987.

That is where I met Dianne, who became my wife. We were married August 22, 1987. At first marriage wasn't easy. I had to work out the problems of being married with prayer and counseling and attending workshops on marriage and special classes on parenting. It wasn't easy.

Now Dianne and I have five children, two of our own, and three adopted. Dianne is a teacher at the Colorado School for the Deaf and Blind and I'm a Mr. Mom. I stay home and take care of the house and the children.

Kevin and Dianne on their wedding day.

A GLOVE THAT TRANSLATES

By Mindy Sink

(Reprinted from The New York Times, February 7, 2002)

Editor's Note: Though the following article deals specifically with a device being developed for deaf consumers, readers may find it interesting because it appears possible for deaf-blind persons to use such a device too. It could possibly be modified for those who do not have facility with spoken language.

Necessity may have been the mother of Ryan Patterson's invention, but hunger played a role, too.

Mr. Patterson, 17, was at a Burger

King restaurant in the summer of 2000 in his hometown of Grand Junction, Colorado, when he saw a group of deaf people buying their meals. Rather than try to communicate with the cashier, they used sign language with a speaking person who placed their orders for them.

Out of that experience Mr. Patterson, a high school senior, developed a sensor glove that can take the finger movements of American Sign Language and translate them into text on a small display screen. The invention earned him a top award last December in the Siemens Westinghouse Science and Technology Competition and similar honors last spring at the Intel International

Science and Engineering Fair.

Mr. Patterson did not know anyone who was deaf or mute. Nor did he know any sign language. But aside from his experience at the Burger King, he had read about a student in Grand Junction who had an adult translator with her in high school, with the school district picking up the cost.

"There is a very high demand for translators, and they are very expensive and hard to find," he said. "I thought this might be a way for them to be more independent."

So using a golf glove, a circuit board, a laptop computer and some basic electronic parts, Mr. Patterson, who worked on his first electronics project at age 5, created the Sign

Translator for a local science fair. He has since refined the device, replacing the laptop with a small wireless receiver and display unit, and applied for a patent for it. One company has inquired about manufacturing the glove, he said, but he is looking into doing that himself.

In conceiving the project, Mr. Patterson realized that he would need sensors that could read the positions of the fingers. But the sensors, flexible strips of carbon-coated plastic that act as variable resistors, needed to be attached to something. He chose a golf glove because it has full fingers and is made from thin leather, making each sign easier to discern. Thinness also proved useful when the 10 sensors were sewn on the glove's fingers and wrist.

But how could a computer know whether a hand was shaping a B or an E? Mr. Patterson designed a software program that could "learn" individual letters or words, making calculations based on the distance between the fingers and hand. A small processor and transmitter attached to the back of the glove send signals to the display unit.

Because people's hands vary in size and because signing, much like voice inflection, can vary from person to person, the software learns an individual's quirks over time. Then the glove is ready to go into action, translating finger movements in about one-fifth of a second.

Mr. Patterson said that the device was not intended for one-sided, brief interactions. "It's for running errands like going to the cleaners or ordering food or being in the classroom," he said. "There's no replacement for a human translator, and people who can't speak are going to need one at some point."

Technology has already found a niche in the deaf and nonspeaking world. "This sounds a little like our digital pagers, which are ubiquitous on campus right now," said Mercy Coogan, director of public relations at Gallaudet University in Washington, which was founded exclusively for the deaf and hard of hearing. "This device sounds like people would no longer have to fidget around for pencil and paper to write things down when they want to communicate."

BLIND AND DEAF MAN COMPLETES MASTER GARDENER COURSE

(Reprinted from The Grand Rapids Press, Michigan, April 2002)

DETROIT (AP) Roderick Gordon, the first blind and deaf person to enroll in the Michigan Master Gardener Program, recently finished the 12-week course. He was one of 34 students in the class, which met for four hours weekly at the Wayne County office of the Michigan State University Extension in Detroit.

At each class session, two interpreters assisted Gordon. While lecturers described the details of plant diseases, lawn maintenance or soil preparation, the interpreters moved their fingers and palms against Gordon's, translating spoken words into information he understands.

A classmate's notes and the Michigan Master Gardener notebook, the statewide gardener education program's textbook, were sent to Michigan State University and returned to Gordon in Braille, as were the tests. Mary McLellan, state master gardener coordinator, said the $1,200 cost of translation was paid by the state program, which will keep the materials in East Lansing so others may use them. The Master Gardener course is open to all who can complete it, plus the required 40 hours of volunteer work.

Gordon, 50, who had tumors that cost him his vision at age 27 and his hearing at 35, had called around looking for pots to use on his Detroit apartment's balcony when directory assistance gave him the number for the Wayne County Extension office. He reached Kristine Hahn, a consumer horticulture agent. Hahn and Gordon communicated over the phone with a telecommunications device and the assistance of an operator from the Michigan Relay Center who monitored the calls.

She put Gordon in touch with a

Detroit man who assists gardeners with special needs. The two men discussed the Master Gardener course, and Gordon called Hahn again, saying he would like to enroll.

Hahn talked with McLellan and a number of agencies that serve people with disabilities to devise a plan for the Braille translations as well as the pair of interpreters required for each class.

Gordon grew up in Jamaica where he worked as a machinist until his sight became impaired and he sought medical consultation in Detroit, where his sister lives. He went through a training program for people with visual impairments and took classes at Wayne State University, studying computer science and business administration.

Interviewed through interpreters, Gordon said he is considered totally blind and profoundly deaf but "I still have what God wants me to have."

Gordon and Hahn have not decided how he will earn his volunteer hours but he is already sharing what he learned in the class. The Master Gardener program "was a very remarkable course. I would recommend it to anyone in Michigan," said Gordon, who plans to grow vegetables, herbs and flowers on his balcony this year.

Hahn said she hopes Gordon will inspire others. "I would like him to encourage disabled people to garden and show them how to do it, she said. "It is something they can do. As most gardeners know, gardening is extremely therapeutic. There is such a sense of accomplishment."

HER VISION: RESTORE HISTORY

By Lisa Chamoff

(Reprinted from NY Newsday, March 2002)

A campaign is under way by a resident of the North Fork of Long Island to restore a crumbling, boarded-up Southold cottage rented by Helen Keller and Anne Sullivan the summer before Sullivan died.

The landlord, Suffolk County, has approved the cottage's demolition, but is willing to work with Mattituck resident, Helise Flickstein, if she raises funds for the restoration and maintenance. Flickstein is looking to turn the home into a museum.

"My vision is to see school buses pulling up and visiting the home," said Flickstein. "I truly believe it does have historic relevance. She (Keller) is an important part of our American history."

Sullivan, who had operations to help her overcome vision problems, became Keller's teacher and companion. Keller, Sullivan and Keller's secretary, Polly Thompson, rented the cottage during a vacation in the summer of 1936 when Sullivan was ill. Her doctors had advised her to exercise and get some sun.

One day, when Sullivan was wading in Peconic Bay, she collapsed from a heart attack and was rushed to a hospital. She died a few weeks later.

Olive Rogers Penfield of Southold, whose father purchased the house in 1933, remembers seeing Keller and Sullivan at the cottage. "Miss Keller was aware of everything around her - the water, the trees, the fact that we had a dog," said Penfield, who was 8 years old at the time. "It's a shame. They just let the house go to wreck and ruin."

Penfield said her father also rented the eight-room Tudor-style cottage to Owney Madden, the owner of New York's famous Cotton Club, in the 1930's.

Suffolk County purchased 62.5 acres of land, which included the cottage property, in the 1960's and turned it into Cedar Point Park. Two years ago, the town of Southold requested that the house be made safe, and the county subsequently voted to approve its demolition.

There is no scheduled plan to raze the house, said Peter A. Scully, commissioner of the Suffolk County Department of Parks, Recreation and Conservation. "If, in fact, restoration is possible, it's something we'd be very interested in."

The rear of the building, which was constructed in the 1920's, has since collapsed and there are several holes in its roof. Flickstein said she hopes to collect private donations to restore and preserve the cottage. "We'll listen to see if there's a way to share the burden or a way to amass resources like grants," Scully said. He added, however, "that doesn't mean the house is in good enough shape to be restored."

Helen Flickstein in front of the Southold cottage.

A SCHOOL FOR BLIND AND DEAF

By Judith Lester

(Reprinted from the Naples Daily News, Naples, Florida)

Every Sunday morning at 10:30 along Pine Ridge Road nearly half a dozen Collier County students line up to climb aboard a school bus. They're about to ride for seven hours to return to the Florida School for the Deaf and the Blind in St. Augustine.

Julio Alvarado is a 14-year old deaf student who rides the school bus. Julio has had 22 corrective surgeries since he was 10 months old that stemmed from severe genetic birth defects.

Before Julio went to St. Augustine, his mother says, he had one friend aside from his brothers and close family members and he didn't get excited about going out in public.

The Florida School for the Deaf and Blind is the only public school in Florida that educates deaf, hard of hearing, blind and visually impaired students. Julio is still shy, but has changed a lot since he started attending the St. Augustine school, says Olivia Alvarado, his mother. "He comes home for the one full day we have him (Saturday) and is ready to get out and go shopping and do whatever," she says.

The School for the Deaf and the Blind was founded in 1885 and is the largest school of its kind in the United States and is home to nearly 750 students. Five hundred kindergarten through 12th graders are housed in dormitories during the week and return home each weekend. The school serves as a statewide resource center to more than 60 families of newborn deaf and blind infants.

There are nearly half-a-million special education students in Florida who are identified as blind and deaf. While impaired children may have access to adequate support services in the larger school districts, medium and smaller districts are challenged in retaining certified teachers and support staff to educate the deaf and blind. "We went to St. Augustine because at school (in Naples), he was just not going to benefit, he was being passed over," Olivia Alvarado says.

On an academic level, the school mirrors programs offered in regular public school districts. Classes are specifically designed to instructional strategy, technology, materials and curriculum.

Katie Worsdale is another 14 year old deaf student, from Marco Island, who makes the journey each week to St. Augustine. Katie is an eighth-grader who has Waardenburg Syndrome.

Both families concur that the school has made an impact on their children's lives and their education. "The benefits are being around kids that are just like him and that he can get along with kids that he can communicate with," Olivia Alvarado says.

The School for the Deaf and the Blind opened a lab in 1996 that is specifically equipped for deaf and hard-of-hearing students. The lab is a unique classroom environment that includes modern work stations that blend computers with telecam, video discs and workbooks. Students work independently, setting their own goals, keeping their own records and managing their own exam work. Julio has interests in possibly working in computers one day.

Students also participate in drama, dance, chess, Little League, basketball, music, football, canoeing, rock climbing, skate boarding, swimming, cross country track, volleyball, girls soccer, wrestling, tennis and golf. Julio Alvarado participates in weight training and track at school.

More than 75 percent of the Florida School for the Deaf and Blind graduates continue their education at colleges, universities and technical training centers.

Katie says she wants to teach sign language to children when she gets older.

SABENA AIRLINES REFUSES TO ALLOW DEAF-BLIND MAN ON PLANE

By Stacy Nowak

(Reprinted from Silent News)

Editor's Note: For years, deaf-blind

travelers have had difficulty in traveling alone on various modes of transportation, particularly the airlines. The following article should remind readers that, despite progress made in alleviating this problem, deaf-blind travelers should be aware of such problems if they plan to "go it alone."

Traveling by airplane is not a favorite pastime for many, especially with the heightened fears since the September 11th attacks. For Deaf-Blind people, traveling is not an easy task. Even so, Deaf-Blind people ask for no pity, and many have logged thousands of miles - whether it be by air or by ground. When they can't travel, it often isn't because of their disability, but because other people don't let them. Arthur Roehrig of Washington, D.C., found this out the hard way recently.

Roehrig, a leader in the Deaf-Blind community, made plans to travel to Rome, Italy, for the Deaflympics last summer. Making reservations long before the planned travel date, Roehrig made sure that the chosen airline, Sabena Airlines, was aware of his disability. A few days before he was to depart, a phone call was placed to Sabena to ensure assistance for the flight.

Upon arrival at Dulles Airport, Roehrig was introduced to a Sabena crew member identified only by the name of Mary. He was told that Mary would be assisting him throughout the departure procedures. Roehrig had a Deaf-Blind interpreter with him upon arrival at the airport. He asked Mary if the interpreter could accompany him on the shuttle bus to the next terminal so that the interpreter could explain Roehrig's needs to the flight crew. Mary told him that it was not necessary and that she would do it herself - then she escorted him onto the shuttle and onto the airplane.

Unfortunately, Roehrig fastened his seatbelt a little too early because Mary asked him to stand up and come with her. Before long, he realized that Mary was leading him off the plane. Roehrig tried to ask what was happening but, according to Roehrig, she refused to talk to him. He was escorted back to the main terminal then asked by Mary to take a cab home.

Roehrig became very angry and another crew member arranged for Roehrig to fly to Italy on another airline. The trip went smoothly, and Roehrig returned to the States on a Sabena flight without difficulty.

In a statement shared with the general public, Roehrig presented an excerpt from the Air Carriers Access Act (49 U.S. Code 41705) that explained that airlines may not discriminate against individuals with disabilities. The United States Department of Transportation has such laws in place to ensure that the incident with Sabena is one that calls for dire consequences on the part of the airline. As a result of the incident, Roehrig has filed a formal complaint against Sabena Airlines. The formal complaint has been shared with the United States Department of Transportation, the United States Department of Justice, and the National Association for the Deaf, along with several newspapers, organizations and groups catering to the deaf-blind.

Roehrig is not alone in his battle for independence. In 1996, a Deaf-Blind woman was denied a seat on a Continental flight due to her disability. She filed a lawsuit in federal court, and the federal jury found Continental guilty of violating regulations. Although no monetary damages were awarded, this case was a turning point in the fight for rights for Deaf-Blind people. Yet, five years later, equal access is still not the case.

In addition to Roehrig, travelers with disabilities were greatly affected by the tragedies of September 11th. Due to major changes in air travel, accessibility became an issue. For example, airlines no longer allow curbside check-in and drop-offs. Because of this, Deaf-Blind people must have full access to "meet and assist" services at each airport. Moreover, Deaf-Blind people often need assistance until they are seated in the aircraft. Suggested resolutions include security procedures allowing this to become a standard and smooth process, and informing and warning people with disabilities of new security measures in the most effective communication methods possible.

The National Association of the Deaf has been working closely with the National Council on Disabilities to make sure that people with disabilities are given equal and fair access to privileges enjoyed by other travelers. Meanwhile, Roehrig waits to hear from Sabena. He has no plans to stop traveling.

DEAF-BLIND VETERINARIAN EXCELLS USING ASSISTIVE TECHNOLOGY

Human Awareness News
Spring 2002

Dr. Medleau

A professor of veterinary medicine honored for her teaching and research at one of the nation's most prestigious academic institutions acknowledges she wouldn't be working at all without the benefit of technology.

Linda Medleau, D.V.M., M.S., is a professor of veterinary medicine at the University of Georgia (UGA), Athens, where in the year 2000, she received the campus's Josiah Meigs Award for Excellence in Teaching, the highest honor the university bestows. She additionally has been a Lilly Teaching Fellow, recipient of the College of Veterinary Medicine's Norden Distinguished Teacher Award, a keynote speaker, a visiting scholar in Germany, and editor of numerous journal articles, textbook chapters, and a best-selling veterinary dermatology textbook. She also happens to be one of only 70,000 Americans who are both blind and profoundly deaf.

She attributes her determination and her impressive list of academic credentials to two advisers - her ninth-grade guidance counselor who suggested channeling her interests in biology and animals into a career in veterinary medicine, and an assistive technology counselor who a few years ago told her, "It doesn't matter how you do the job, as long as you get it done."

Born with sight and hearing, Medleau was diagnosed during her teenage years in Cleveland, Ohio, with a hereditary disorder called Usher syndrome III that first manifested itself in a noticeable decline in auditory function when she was in fourth grade. She compensated for her deteriorating hearing by sitting near the front of her classrooms, deliberately coping without a hearing aid until age 15.

"Because I was hearing-impaired

and missing a lot without realizing it, I was really socially awkward. And I felt most comfortable around animals," explained Medleau. In high school she began having difficulty seeing at night. Upon her graduation, doctors at the National Institutes of Health in Bethesda, MD, confirmed the onset of retinitis pigmentosa, an untreatable condition causing degeneration of her retinas. They told her that the condition wouldn't seriously affect her vision until she reached her 60's. They were wrong. Medleau decided that she would not allow her deteriorating vision to interfere with her plans to pursue a career in veterinary medicine.

Following her graduation from Ohio

State University with a D.V.M. degree in 1979, she served a one-year internship in veterinary medicine and surgery at Michigan State University, concentrating on dermatology. She chose that discipline after weighing her options. "I knew I wasn't going to be able to become a surgeon because people wear masks during surgery and I wouldn't be able to understand what they were saying," she said.

After obtaining a Master's in Immunology at the University of Georgia in 1982, she completed a two-year residency in dermatology at the University of Pennsylvania and promptly returned to UGA, this time joining the faculty as a specialist in small-animal dermatology.

She managed to work without assistive technology until 1992, when she found it necessary to begin using a radio assistive listening device because her hearing aids were no longer sufficiently amplifying questions from students in the lecture room. A teaching assistant in her small-animal dermatology classes relayed questions from students into a small transmitter unit, and Medleau heard the question through the receiver's headset.

When she no longer could read without assistance, she began using a video magnifier as well as ZoomText on her computer to magnify text. That worked - for a while. "I couldn't use magnification anymore; it was so incredibly fatiguing. I could get text large enough, but I could no longer get it focused," said Medleau.

She turned to the Helen Keller National Center for Deaf-Blind Youths and Adults in Sands Point, NY, where she met an inspirational assistive technology counselor who encouraged her to explore other methods to accomplish her goals. The counselor recommended assistive technology products, including several available through Pulse Data HumanWare.

Following the counselor's advice, Medleau obtained a new computer with Microsoft Windows, screen-reading software, a scan-and-read system, a braille embosser, and a 45-cell braille display, which she was able to use because she had begun studying braille two years earlier.

"The funny thing is, when I stopped using my eyes, I found I had a lot more energy," she said. To give her portability, she's now purchased a Pulse Data BrailleNote personal data assistant with a QWERTY keyboard, which she prefers.

"I don't have JAWS on the computer at home because the whole family uses it, so I was unable to work there," she said. She chose the BrailleNote rather than installing JAWS for Windows on her laptop computer and buying another 45-cell braille terminal. "Even though the laptop is supposed to be portable, the thought of having to unhook the cables every day and schlepping it and the braille terminal back and forth made me nervous. So when I contacted HumanWare and explained my concern, they suggested the BrailleNote because of its portability and its built-in braille display," said Medleau.

Medleau's field of vision is now reduced to a dense, shadowy fog of only 5 degrees, and her hearing loss is nearly 100 decibels, just 10 decibels less than total deafness. Even so, she's found ways to compensate during the clinical work she performs with people's pets six months of each year, in the university's Small Animal Teaching Hospital. She is accompanied on her rounds by veterinary residents, interns and senior-year students who describe the conditions they observe and discuss the clinical history of patients. After Medleau herself examines the affected area of an animal's skin with her hands, she confers with her accompanying residents and students about the likely possibilities and prescribes a treatment. A dermatology technician helps Medleau perform procedures that she no longer can do. Medleau's students praise her for encouraging them to use all of their senses - hearing, touch and smell, as well as sight - in examining patients.

Medleau may have, indeed, lost nearly all of her eyesight, but she retains a sharp sense of the vision she had in ninth grade when when she made the determination to help animals and the people who love them.

HERE AND THERE

NEWSREEL is a monthly audio magazine for the blind and visually impaired that contains news, information, articles of interest, and entertainment. For more information and a sample copy, contact NEWSREEL MAGAZINE, East Long Street, No. 420, Columbus, OH 43215. (588) 723-8738

* * * * * *

The Braille Institute of America is offering free copies of EXPECTATIONS, an anthology of short stories for children produced in braille. Call (213) 633-1111 or write: Editor, Expectations, Braille Institute of America, 741 North Vermont Avenue, Los Angeles, CA 90029-3594.

* * * * * *

The Recipe of the Month Club is a new service providing five new recipes per month in any format of your choice - braille, large print, computer disk, or e-mail. Members also get unlimited recipe search and transcription service. To join, send a check or money order for $25.00 payable to Maureen Tranghofer, Recipe of the Month Club, 4910

Dawnview Terrace, Golden Valley, MN 55422. For questions or to request transcription of a print recipe, call Maureen Tranghofer at (763) 522-2401.

* * * * * *

Vision Community Services, a division of Massachusetts Association for the Blind, offers custom braille transcriptions. Recent work includes menus, financial statements, user guides for consumer electronics, presentation hand-outs and hymnals. While Vision Community Services specializes in shorter documents to save turn-around time, it also produces some longer documents. If you wish to have documents transcribed into braille, or have any questions, contact Bob Hachey, Braille Program Supervisor, Vision Community Services, 23A Elm Street, Watertown, MA 02472 or call (617) 972-9101.

* * * * * *

The new Krown Braille TTY was specially developed for deaf-blind users to allow them to communicate with a relay operator, a TTY or another Braille TTY user by having the conversation displayed on a refreshable braille display from the Alva braille terminal. The braille display has a 21-cell 8 dot braille navigator.

Developed by Krown Manufacturing, the braille TTY connects directly to the phone and comes with built-in auto-answering nine speed dial memory numbers, five programmable memory buffers with up to 8000 characters each. The rechargeable battery of this portable unit will last for six hours. It comes with a carrying case for easy storage.

The ASCII option allows the user to connect with a data-based caller. The Braille TTY user is able to switch between braille and or TTY modes for convenient typing. It also comes with software and cable to connect the Braille TTY to a personal computer.

The unit sells for $6,459.00. For

more information, contact Krown Manufacturing, Inc., 3408 Indale Road, Fort Worth, TX 76116. (817) 738-2485 (TTY) (817) 738-8993.

* * * * * *

EnableMart (www.enablemart.com) offers assistive technology for everyone - including voice-input software, modified wireless keyboards, screen enlargers and readers, mobility devices and more.

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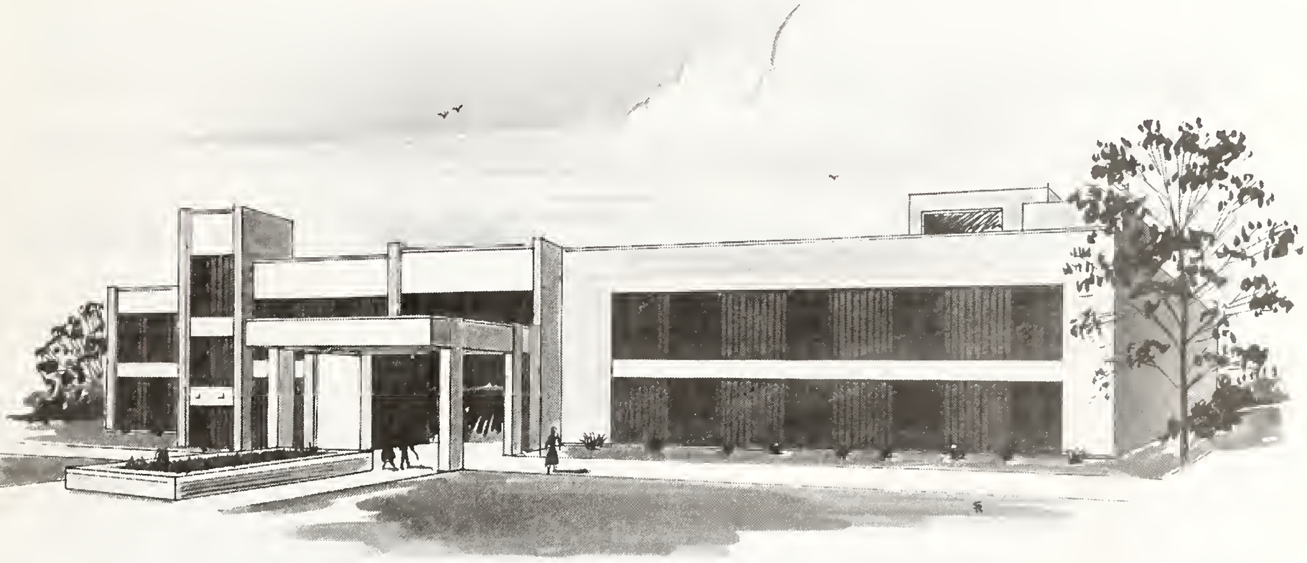

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EDITORIAL: TAPPING RESOURCES

By Robert J. Smithdas,
LHD, Litt.d, LHD

The written word is still the most important tool for us to learn about this world we live in. It is still the most basic method of recording all phases of human history and documenting humanity's progress and achievements. Books and articles provide valuable sources of information, instructions for living, entertainment and pleasure, and a parade of historical figures and scenes that give us a glimpse of bygone days.

For a long while now, we have included in NAT-CENT NEWS materials written about and by successful deaf-blind individuals who have overcome the problems of living without sight and hearing. Unfortunately, we cannot include the longer, more explicit stories of such individuals who have surmounted barriers to independent living through sheer personal determination and ingenuity. Reading through past issues of NAT-CENT NEWS, one realizes that today, in modern times, there are dozens of success stories that are waiting to be collected and made available to us for the wonderful examples of how individuals have learned from education, training and experience and use their initiatives to succeed.

There is a growing horde of information about remarkable deaf-blind personalities who have achieved outstanding goals. Beside the books and articles of Helen Keller, we now have a trove of writings by others - a biography of Richard Kinney, THROUGH THE RAIN AND THE RAINBOW; Aslaug Haviland's THE STORY OF ASLAUG; and Geraldine Lawhorn's autobiography, as well as the recent books written about Laura Bridgman, the first deaf-blind child to be educated in this country. And there are still untapped stories of deaf-blind individuals who are currently teachers, rehabilitation workers, or owners of small, entrepreneurial businesses.

Finding enlightening materials that can benefit deaf-blind education and rehabilitation and provide examples of how deaf-blind individuals solve problems that confront their independence is not limited to simply scouring the literature here in the United States for pertinent materials. Other countries are also making advances in the same basic areas for their own deaf-blind programs, and it would be a great addition to our knowledge if we had input from the educators who have contributed to education of the deaf-blind.

JULIA IS DEAF AND BLIND

Reprinted from the Peterborough
Evening Telegraph,
Peterborough, United Kingdom
By Kelly Swift

She's deaf and blind, but Julia still cares for three kids, three hamsters, four chinchillas, eight rabbits, four guinea pigs and a dog. It's hard enough being a deaf-blind mum, but imagine having to look after 20 pets, too. One remarkable woman tells reporter Kelly Swift how it's done.

It was a beautiful spring day as I approached Julia Kimbell's Peterborough home. But as I prepared to interview the mother of three, I realized the only knowledge she had of the lovely March afternoon was the warmth of the sun on her face. For Julia is both deaf and blind.

Most of us have five senses, but Julia, 40, has only got three and the two she is missing are the ones the rest of us would miss most of all. She has never seen her children smile, never heard their laughter. She has never heard them shriek with delight, and never seen their tears. Running a household with three children under 10 is a challenge for any mother, but for Julia, with a little help from her husband John, it has become second nature.

Her home is just an ordinary 3 bedroom terraced property in Orton Malborne. It is occupied by an ordinary family including Julia's three children, Ayla, 9, Ricky, 7, and Jordan, 3, as well as three hamsters, four chinchillas, eight rabbits, four guinea pigs and a dog called Gypsy.

So how does this remarkable woman cope? Well, after spending just a few minutes in Julia's company - apart from the interpreter by her side - it would be easy to forget she is deaf and blind.

She speaks clearly and concisely, has a wicked sense of humor and laughs and jokes with you. When asked how she coped with getting her children ready for school, she grinned - "Badly". She added: "Ayla is old enough to get herself ready, but with the boys, I rely mostly on touch - if they have something sticky on their clothes, such as yogurt, then I can feel it."

John, 44, does not work and cares for Julia and the children full-time. In addition, Julia has a "mother's help," Alanah Blackmore, who helps her in the home from Monday to Friday.

Their oldest son, Ricky, is mildly autistic and is going blind. He was diagnosed with retinitis pigmentosa (RP) when he was just one. RP is a hereditary disease which involves the progressive deterioration of the retina, the light-sensitive layer that lines the eye.

I asked Julia if she ever gets angry about Ricky losing his sight. She said, "No, I knew the risk I was taking when I had kids. There is no reason why he can't lead a normal life. It would have been harder if he was deaf, but at least he can communicate with others."

Julia lost her sight when she was six or seven and her hearing when she was 20, but this does not prevent her from communicating with her children. Ayla has learned to use the deaf-blind manual alphabet - more commonly known as fingerspelling - although Julia said her spelling sometimes lets her down and she makes "no sense at all."

Ricky relies on dad to ask mum questions for him, and little Jordan has learned to manual "yes" and "no" on Julia's hand.

She added, "Like with any children, they soon let me know if they need anything. If Jordan wants a drink, he will grab my hand and take me to where the drinks are kept."

With Julia and John living in each other's pockets 24 hours a day, you could be forgiven for thinking this would put their marriage under more strain than most. Julia, who has been married to John for seven-and-a-half years, said, "The trick is learning to accept each other as you are and work together. He does the cooking and I do the washing up."

The home is filled with family pictures and the children's happy, smiling faces are testimony to Julia and John's love and devotion to them. But Julia is unsure whether or not her children have been disadvantaged by her condition. She said, "Sometimes I miss not being able to take Ayla out to the shops. They grow up so quickly and get into fashions at such a young age now. I would love to be able to take her clothes shopping, although we would probably disagree on colors. Jordan is the one who gets the most frustrated because he can't speak to me and I get equally as frustrated. But someone usually comes to the rescue and Ayla will often help interpret. I love to play with the children and I am a big kid. I love getting on the floor with Jordan to play with Lego, or Barbie with Ayla. I just think 'hell, why not' - they have nicer toys than we did."

Julia cannot see her children, just like she cannot see the spring flowers. But Julia still has her sense of touch and is determined to enjoy the pleasures of life, just like the rest

Julia and a guide-communicator from Deafblind UK of us.

Charity helps Julia live an independent life. Julia has often helped publicize Deafblind UK, the Peterborough-based charity she credits with helping her live independently. Recently, she took part in the Peterborough Half Marathon, and walked the 13-mile route to raise awareness and sponsorship for when she will take part in the London Marathon.

Jo Johnson of DeafBlind UK said: "Julia is a remarkable lady and a credit to the charity. Working with people like her make it all worthwhile." To find out more, visit the website at www.deafblind.org.uk

ASSISTED LIVING FOR DEAF ELDERLY IS LONG TIME DREAM FOR WOMAN

By Eric Mortenson

Reprinted from the OREGONIAN,
Portland,Oregon

There are days, Mae Johnson says, when she walks into her new building and begins to cry because the dream has been so long in coming. And now here it comes: an assisted living facility for elderly deaf and deaf-blind people, the first facility of its kind in the Northwest and only the second in the nation.

The four-story facility, called Chestnut Lane, will open this summer at Northeast 6th Street and Cleveland Avenue adjacent to the light-rail line. Fifty of the 70 apartments have already been reserved, an indication of the enthusiasm for the project within the deaf community, Johnson says. Most of the residents will be low-income; 54 of the apartments are set aside for people eligible for Medicaid housing supplements. Advocates say deaf elderly are particularly vulnerable in traditional nursing homes and assisted living facilities which rarely employ staff who know sign language. Unable to communicate, deaf elderly can become isolated and depressed.

Johnson says Chestnut Lane will provide a safe, supportive environment. Because it is adjacent to a MAX station and within a couple of blocks of the new Multnomah County building, residents will have easy access to shopping and services. "Being in a safe community and going out from there is the whole plan,"Johnson says.

A market study conducted two years ago showed there are close to 2,000 deaf people older than 65 in the Portland-Vancouver area. Nearly 300 of them had health problems that made them eligible for an assisted living facility, the study showed. Although people are excited about the facility opening, Johnson says, the event is tempered by anxiety. Because there's nothing to compare it to, she says, some elderly deaf wonder if it might be like the controlled atmosphere of the institutional deaf schools many of them attended as children. She tries to reassure them that Chestnut Lane will operate more like an apartment complex, with the residents free to come and go.

Johnson's had a good response from

deaf people who want to work at Chestnut Lane - 63 applications for 26 jobs. The deaf are chronically under-employed, and the opportunity to work in a setting where they can converse with other employees and with residents is appealing, Johnson says.

The $8 million building has several features designed for deaf and deaf-blind residents. The fire alarm system has flashing lights; rooms for residents who are also blind will have vibrating beds that will wake them in an emergency. Each room has space for a TTY - a text telephone.

A computer room shared by the residents will have equipment for video conferencing so residents can use sign language instead of typing. The nurse-call system in each room provides a digital readout rather than a traditional intercom.

The size of the facility's first-floor living room was cut in half from the original design. Deaf prefer to talk in small groups because sign language conversations can get jumbled in larger settings, Johnson says.

Smaller gathering spaces, with room for a card table or simply a couple of chairs, are scattered throughout the building. The rooms come with refrigerators and microwave ovens, but residents will take most of their meals in a dining room on the top floor. A community room on the third floor could be used for meetings, church services or sign language classes, Johnson says.

Other features include a small library, beauty salon and laundry. Room 218, a one-bedroom apartment in the southeast corner near the library, will be home to Johnson's parents, Ray and Jeanne Jordan. They are the reason Johnson decided to build the facility in the first place.

Johnson, a registered nurse who knows sign language, got the idea after encountering an elderly deaf woman who was dying of cancer. The woman told Johnson she'd rather die at home than be isolated in a nursing home where no one could sign. That started Johnson thinking about her parents, both deaf and in their 70s.

Checking with acquaintances who have deaf parents, she discovered no one had a plan for their parents' care. She opened a foster care home for deaf elderly - the first one in Oregon - and soon had a waiting list 15 people long. The dream of opening Chestnut Lane grew from there.

Although Johnson has no development experience, she linked with a consultant who helped her cobble together funding from the State Housing and Community Services Division, the City of Gresham and Multnomah County.

Johnson's parents, who now live in a mobile home park in Hillsboro, are anxious for the facility to open. Her mother rides MAX to the construction site every two weeks to take pictures of the progress, and is planning where her furniture will go. Her father has his plans, too. "Daddy wants to be next to the library so he can go out and get his Zane Grey books anytime he wants," Johnson says.

A FIRM HOLD

By Lem Satterfield

Reprinted from The Baltimore Sun,
Baltimore, Maryland

Blind and nearly deaf, Loyola High's Nikos Daley has been able to grasp a little glory and much satisfaction as a junior varsity wrestler.

Preparing to take on his opponent from visiting McDonogh, Nikos Daley was unaware he was about to face Cory Haugh, the same wrestler who had pinned him in less than a minute during a previous match. Loyola High School's junior varsity coach, Steve Thompson, escorted Daley to the center of the mat for the neutral, standing start. The referee motioned the McDonogh wrestler forward and instructed both boys to touch palms, leaning closer to Daley so he was sure to understand what was said.

Daley didn't recognize the other boy because he couldn't see him. He heard the words only faintly because he is almost deaf and his hearing aids won't fit under his wrestling headgear.

Daley, 16, has been blind since birth. His hearing loss is believed to be linked to the same congenital condition. Despite his disabilities, the Loyola sophomore is an upbeat achiever, supported in his drive for independence by his family, friends, teachers and teammates.

"That he has the ability to perform as he does is absolutely amazing," said Dr. Theda Kontis, an otolaryngologist, or ear, nose and throat specialist, who became Daley's physician in 1999. "He talks and acts like there's nothing wrong. He handles his disabilities better than anyone ever could."

Daley was born in Greece and spent his early years in an Athens orphanage. He is one of five children adopted by Peter and Alex Daley, and the youngest in their family of nine children. Older brothers Tom and Paul, both 21, preceded him at Loyola, where they were wrestlers and football and lacrosse players.

Said Peter Daley of his youngest son's wrestling career: "I'm impressed with his progress. It'll take a lot more hard work than other people, but he'll get his share of wins."

On this afternoon against Haugh, Nikos Daley was not yet skilled enough to get a win. The pair was poised in the legal position for bouts involving blind wrestlers, "one palm down, one palm up, touching the other person's hand up to your knuckles," as referee Biff Davison described it.

Haugh, having wrestled Daley before, knew the drill. "You can do anything like in another match, except you have to maintain contact," the 125-pound junior said. But this time, Haugh noticed, Daley had improved his defenses. "Obviously, being blind, it's going to be tough for him," Haugh said. "But he's going to get to wrestle every match the same way - but for a person who isn't blind, it kind of takes you out of your element."

Haugh, 17, pinned Daley in the second period, after gaining a new level of respect. "I finally got the half-nelson in, but it was tough. This time, he was stronger." And wiser. "When I lost the first match, I went back, tried to figure out what went wrong," Daley said.

Only afterward did Daley discover that he had been in a rematch. He said he hoped to meet Haugh once more that day to "get my revenge." Instead, he faced 16-year-old Quin Pierson.

In their exhibition bout, Daley was on his back three times as he fought off Pierson, a junior, who got the pin with 23 seconds left in the match.

In contrast to opponents such as Haugh and Pierson, who have wrestled continuously for years, Daley most recently competed in a recreation council in eighth grade. This season, his first as a high school wrestler, he finished with four wins in 12 tries after going 2-2 in a junior varsity tournament at Archbishop

Curley. Daley skipped competition as a ninth-grader to allow himself to get used to high school.

Daley is the only blind student to ever attend Loyola said Debbie Cotter, Computer Science chairwoman and director of Educational Technology, who meets with him daily to oversee his instruction.

Nationally, there are 56,000 blind or visually impaired children, according to the U.S. Association of Blind Athletes. In Maryland, the organization has 17 members who compete in high school sports, said Nicole Jomantas, communications director. Daley's mother said she is not aware of his belonging to the Association.

At Loyola, Daley earns mostly A's, mastering academics with the help of a braille note-taking device and a system that assists his hearing. His teachers wear a type of microphone that transmits signals directly to his hearing aids. Classrooms are marked in braille so Daley can identify each room.

"But he has learned these things by direction. And he does use a cane," Cotter said. "He's come miles since he was first at Loyola. He was a timid little guy who needed someone else to get from class to class - but he needs no one now."

Cotter, who describes her role as "almost like a mother-child relationship" with Daley, is but one of several professionals who have nurtured him. Another is Bronwyn Welsh, an employee of the Baltimore County schools who teaches braille. "I don't really think I've told him," said Welsh, who instructs Daley once a week, "but he's the one who got me doing this."

Ten years ago Welsh was his first-grade teacher at Reisterstown Elementary. "That was the year they started inclusion, saying that all children, regardless of their disabilities, should be in a regular classroom. I had never been around a blind person," she recalled, but she improvised, coming up with various tactile teaching methods. She also tricked him into becoming more independent. "I would make up bogus notes for him to take to the office, and I would call down to let them know that Nikos was coming," Welsh said. "They would watch for him, and he would just be so proud of himself that he could go down to the office and come back on his own."

Another fan is Daley's Mobility instructor, who said she has taught him use of a cane and related skills "off and on" since he was 6. "I look forward to seeing him every week," said Pam Satterlee-Williams, who said the teen has asked about using the cane to help him ride a skateboard or perhaps a snowboard. "He has guts, an adventuresome spirit, and he's certainly not timid."

That outgoing outlook started at home. Nikos' family has always allowed him to do things physically that anybody else would do. The Daleys would adapt bicycles, making them a tandem. They did all sorts of things. Peter Daley, 58, said his youngest son was encouraged to play outside the family's 11-bedroom house in Reisterstown much like the other eight children. "Even now, there's a series of posts and a chain-link fence that goes down the walk in front of our house," said Peter Daley, a director of human resources for Home Depot in Westminster. "Nikos would hold on to that chain and know if he was at the end. Nikos would use his Big Wheel, drive down, turn around and come back."

Nowadays, he said, his son roller blades to the end of the block. "He roughhouses with his older brothers" said sister Gina Ruppert, 28. "He's not been coddled. He was expected to pull his weight like everyone else in terms of chores and everything."

Alex and Peter Daley are devout Catholics who gather with their children to pray the rosary shortly after Sunday dinner. Around the house are sayings drawn from biblical lessons, such as one painted in red letters in the family room: "Don't forget to be kind to strangers, for some who have done this have entertained angels without realizing it." The saying, said Alex, 56, "basically means everybody's welcome into our house."

That certainly applied to Nikos, a Greek toddler whose picture she spotted in an adoption magazine. But unlike their previous adoptions of four Korean children, the process of obtaining Nikos was lengthy. When Peter Daley brought him from Greece in July 1991, he was a scared 4-year-old who could neither see his surroundings nor have them described in a language he understood. A Greek-speaking friend came over several days later to interpret.

More than a decade later, Nikos still recalls his arrival. "We used to have this sink with a fountain in it that was really cool," he said. "I've always liked water, and I kept turning it on and off. I remember just going through the house, touching everything to see what was there."

"For about a month," Alex Daley said, "we couldn't get him to eat anything but cornflakes."

Nikos wasn't the first to join the Daley family under difficult circumstances. Alexis, adopted at 2, endured a bone staph infection. Kara, who has cerebral palsy, could barely walk when she arrived at 4. The Daleys loved their children through their various problems, but it was tough love.

"My parents wouldn't do everything for

me, which was the best thing for me," said Kara, 20, who played soccer for Sacred Heart. She is especially close to her little brother, helping pick out his clothes and counseling him. "Nikos would have similar problems dealing with people as I did, people laughing and teasing. Since I've already gone through it, I can give advice on what to do or say."

Around his house, Daley is rarely without his best friend and neighbor, Marcus Gillen-Davis, 17, a junior at Franklin High. "He's really been a godsend," Alex Daley said. Playing video games in the Daleys' basement is a favorite shared pastime. "I usually tell him (Nikos) if something is approaching or if someone's getting really close and starts shooting at him - but he takes care of the rest," said Gillen-Davis.

Daley, his fingers moving nimbly on the PlayStation controller, explains that he visualizes the objects on the screen based on the way his friend has described them before. "He tells me what's going on, and I'm used to the sounds. But this one's Final Fantasy 8. I'm really good at this!" What else besides video games does Daley enjoy visualizing? Extreme weather, he replied. "We were almost in a hurricane at the beach once. My mom was freaking out, but I just took it all in. I've seen hailstorms and tornadoes. I've seen blizzards. The sounds of the weather are very interesting," he said, adding that he wants to become a meteorologist.

To help prepare him for the future, whatever the career, Daley and his parents belong to a club, Transition to

Independence, sponsored by the National Foundation of the Blind. It conducts exercises and provides mentors for blind youngsters.

Meanwhile, in the afternoons at wrestling practice, Daley has a mentor in head coach Kenny Taylor, who is closing in on a degree in adaptive physical education. "I have experience working with physically and mentally challenged kids, many of whom were in wheelchairs or had problems that inhibited them from being mainstreamed into a regular school," Taylor said. "What amazed me was how these kids enjoyed life. It's the same thing with Nikos."

"I really like Coach Taylor," Daley said. "He's really glad when you win, not that uptight when you lose, and he's always confident you can do it. He encourages you.

"For the more than two dozen boys on Loyola's wrestling team, Daley's decision to wrestle meant others adjusting to a person who couldn't get around on his own. After one early practice, an assistant coach was supposedly the last to leave but realized Daley was still in the room behind him. Taylor called a team meeting and asked all the wrestlers to help their teammate. "They had seen him pick up his cane and find his way over to the door. They didn't realize he really didn't know where he was. After that, the kids realized he needed some assistance. Since then, everyone's checking to see, 'Where's Nikos?' or 'Is Nikos on the bus?'"

"When he gets into group drills," Taylor said, "whoever is working with him that day is responsible for helping him." At a recent practice, one of Daley's two partners took Daley's outstretched hand and sat him down against a wall out of harm's way. When Daley ran sprints, freshman Alex Keller ran beside him, shouting "left," or "right," to keep him on course.

At one point, however, it appeared Daley's teammates had forgotten him as he took a break between drills. The momentum of two tumbling wrestlers brought them dangerously close to Nikos, one of their legs just missing his head. After drills, "he'll just stick out his hand and wait until he feels your hand before he does anything," Taylor said. "I told him he can't just sit down on the mat like that. He's got to indicate that he needs help."

Later, Taylor walked Daley through a drill, demonstrating moves and winding up the instruction with a sort of pirouette to face his student. "It's a half-step, not a circle. It's like doing the cha-cha," he said. "Then you're ready to attack."

Taylor then critiqued Daley's successful imitation. "That's a nice standup. But get better hand control." Commenting on his progress, Taylor said, "He picks things up fairly quickly, but I like him to do it over and over again."

The next day, Daley was using his moves for real. Daley battled Calvert Hall's Michael Gray, 14, through six minutes of regulation and a one-minute extra session. At that point, Gray said he told himself: "Whoa, he's pretty good." In the 30-second double overtime, one wrestler wins by escaping before time runs out, the other by holding his opponent down for the duration. Daley's arms had grown heavy, and his chest was on fire.

"I was counting the seconds in my head because I was getting tired and I wanted the match to end," he said. "I basically locked my knees around his knee, putting half-nelsons on him. He almost did get away, but time ran out."

Daley's hand was raised in victory, his first win in high school. Gray was among those who congratulated him. "He was really good. He had skills," Gray said. "Just because he's blind doesn't mean he doesn't have strength."

FOR DINERS IN THE DARK, A TASTE OF MYSTERY

By Michael Powell

Reprinted from Washington Post

NEW YORK -- So we're sitting in a trendy little restaurant on another of those Lower East Side streets best known to smack dealers a decade ago, eating tasty dishes that could come with the Ruth Reichl-Gourmet Magazine stamp of approval. If only Ruthie could see them.

The lighting in this restaurant is not subdued, shaded or hiply shadowed. It's nonexistent. We eat in can't-see-your-fingers-in-front-of-your-face inky darkness. "Oh damn!" says the female voice next to you, as a handful of croquetas de Bacalao apparently collides with her cheek. "I forgot where my mouth was."

It's known as Dining in the Dark, and it's the latest groovy thrill in a city that feels more and more like Imperial Rome circa the Caligula administration. We are among 28 people - most an unfortunate decade or two younger than your correspondent - who have paid $89 per head for the pleasure of groping for our dinner. This restaurant, Suba, serves one such dinner each month.

The evening begins with a $10 drink in the lighted ground-floor sitting room. Then you clomp down steel steps into the basement of this former tenement. There's a thick black curtain and waiters outfitted like tres downtown cyborgs, with their black-on-black clothes and night-vision goggles. One takes your hand and leads you into the darkness.

"The short highball glass is the wine," whispers the now-disembodied voice. "The long and slender one is for the water." You don't say!

The trend toward inky eating began in Berlin and jumped the Atlantic in the person of Jerome A. Chasques whose event-planning company is known as Cosmo Party. He's small, red-haired and cherubic, an unflappable man with an accent more Paris than Manhattan. He embraced the idea last year as he and friends hopped aimlessly from one hip East Village restaurant to another. The free-range New Zealand quail, the saffron-soaked Ukrainian artichoke hearts: So predictable.

Darkness, he decided, might improve everything and prove profitable. "It really started like a little game," he explains. "Something out of the ordinary."

The search for food edge is relentless n this age of global cuisine. In Europe, the First Vienna Vegetable Orchestra has taken to blowing carved-out carrots, tapping turnips and clapping eggplant cymbals before serving their instruments a la carte to packed concert halls.

And for several years now a few of New York's hipper sushi restaurants have been serving up blowfish, a tasty delicacy whose internal organs - not the least their ovaries - harbor a potent neurotoxin that's 1,250 times as powerful as cyanide. Bon appetit.

At Suba we sit at two long communal tables (night-vision goggles are not flawless, and management endeavors not to have the waiters tripping over themselves). Our neighbors across the table announce themselves by grasping for - I hesitate to use the word fondling - our hands. Their voices are high and squeaky, and dissolve into gales of giggles. Their dining experience will prove to be . . . nocturnal.

"There's your first course coming over your left shoulder," says the disembodied voice. The waiters don't tell you what's on the plate. Dining in the Dark is all about the sensuality of the texture and palate. The quiver of the unknown makes senses jump like live electrodes. Whatever. Right now that young couple across from us are squealing. It's just as well they don't give us forks.

The first course is - como se dice? - definitely aquatic, with a piquant hint of something (croquetas de Bacalao with chipotle aioli). In the Stygian dark a glass breaks. Everyone applauds. There are no oils, no soups and nothing terribly solid served. Knives are out. "For a brief moment," Chasques says, "I thought of serving steak for an April Fool's dinner." Liability issues and an inability to master the Heimlich maneuver dissuaded him.

The wineglass mysteriously refills once, twice, three times during the evening. "Am I drunk?" a male voice asks. "Aren't you always?" answers a female voice.

Cosmo Party caters to singles, although in fact more than half the diners this night are couples. Chasques says his couples get along better after they've been in the dark together - something about the art of tactile listening. Perhaps. Right now the male voice and the female voice continue to hiss about his drinking.

The second dish comes over the right shoulder. It's phyllo dough and something delicate and - to this diner's view - cheesy (queso de cabra). I identify the third dish as unequivocally fishlike, accompanied by unidentified fungi (salmon a la Plancha with sauteed shiitake). To know whether you're done, one must wave the hand in inelegant circles over one's plate. Should your fingers hit something that moves, eat it.

The finale slides in. A waiter's disembodied hand guides yours to the fork. There's munching and more guessing. "Meat." "Steak!" "No, lamb!" It's charades at the Helen Keller cafeteria. This is Bunuelos de Cordero, a roasted baby lamb in a phyllo dough beggar's purse. Across the table, our giggling young couple has gone entirely silent.

The lights go on for dessert, a host of small candles and champagne traipsed in by the waiters. An Israeli film crew has filmed the dinner with an infrared camera. A grinning cameraman walks over and congratulates our young couple. "You looked," he says, "like you were in the back seat of a Chevy on Saturday night." They smile back beatifically.

The undercurrent among the younger diners is unmistakable at Dining in the Dark, if generally PG in content. Two young men chat about their dinner as they step out onto Ludlow Street.

Dining in the dark was great, says the one. "Yes," replies the other. "Though normally I know what I'm eating."

EXTRAORDINARY PEOPLE: BOB AND MICHELLE SMITHDAS

by Therese Madden Rose.

Reprinted from Dbi Review,
July–December 2002

Therese Madden Rose, Ph.D., is currently a technical assistance specialist with The National Technical Assistance Consortium at Helen Keller National Center, Sands Point, New York. Here she describes the achievements of two of her colleagues, Bob and Michelle Smithdas.

For more than twenty-five years, the staff of Helen Keller National Center in Sands Point, NY, has been privileged to witness extraordinary accomplishments by extraordinary people. Many people with deaf-blindness from all over the country come to the Center as students for periods of training during which they learn skills which assist them in their adjustment to daily life. Several other remarkable individuals who are deaf-blind are professionals on our own staff. Two such extraordinary people are Bob and Michelle Smithdas.

Bob Smithdas achieved notoriety when he earned not only a bachelor's degree, but also went on to earn a master's, and received four honorary doctoral degrees. Hence he became Dr. Bob Smithdas. His life story, however, began long before that. At the age of four and a half, he contracted cerebro-spinal meningitis and lost his vision and nearly all of his hearing. He later became totally deaf.

In his first autobiography, "Life at My Fingertips," he noted that "unable to hear the sound of my own voice, I gradually lost my feeling for the pitch and stresses that give speech its human character." Dr. Smithdas told me that he has "always been content to find out if I could overcome the obstacles of deaf-blindness for myself, and the challenges were the things that gave me my 'highs' because they showed that everything is possible until you prove it impossible! Besides I had a rather stubborn streak when I was a kid, and if you said I couldn't do something, I'd try to prove you were wrong and I was right."

He certainly has done that numerous times. We have all, especially people with deaf-blindness, benefitted from his stubborn streak. With Helen Keller and Peter Salmon, Dr. Smithdas played a vital role in the development of legislation in the USA authorizing the establishment of the Helen Keller National Center for Deaf-Blind Youths and Adults. At the age of 77, he continues to serve as director of Community Education at HKNC.

Bob's sometimes gruff, stubborn exterior is balanced by his sensitive poetry. In "Shared Beauty," he remarked, "I call it Life, and laugh with its delight. Though life itself be out of sound and sight." In addition to "Shared Beauty," Dr. Smithdas is also the author of another collection of poems, "City of the Heart."

Michelle Smithdas was born hard of hearing and became totally deaf at the age of 15. After a snowmobile accident during her senior year at Gallaudet

University, she lost her vision. Michelle met Bob when, in 1972, she came as a student to Helen Keller National Center. Three years later, they were married.

Michelle is an instructor in the Communications Learning Department at the Center. In an interview printed in The Deaf American in 1976, Michelle said that she learned courage and determination from Bob. When Michelle decided to acquire a cochlear implant in 1994, however, Bob kept his opinion to himself until after she had made her own decision. When the implant was turned on, the first sound she heard was Bob's voice. Michelle described the experience as "thrilling."

Like many Americans, Bob has a garage filled with power tools which he uses to make repairs in the home which he and Michelle own. He is also a gourmet cook. Michelle is an excellent baker.

Bob and Michelle enjoy a dance together at the Gala celebrating the 25th Anniversary of the HKNC

American television journalist, Barbara Walters, described her 1988 interview with Bob and Michelle Smithdas as the most memorable of her career. In the November 2001 "Power" issue of Ladies Home Journal, Ms. Walters named Michelle Smithdas as the woman who most inspired her.

On November 7, 2001, Barbara Walters presented the Helen Keller National Center Lifetime Achievement Award to Dr. Bob Smithdas.

Those of us who work in the field of advocacy for people with disabilities sometimes fail to notice the achievements of our colleagues. Because of people like Bob and Michelle Smithdas, doors are open which had not even been approachable during Helen Keller's lifetime. That is truly extraordinary.

LIGHTHOUSE LAUNCHES DEAF-BLIND TECHNOLOGY DISTRIBUTION PROGRAM

Reprinted from HORIZONS, Seattle Lighthouse

Thanks to an appropriation earmarked in last year's federal budget, the Seattle Lighthouse recently began a pilot program to improve technology access in the lives of people who are deaf-blind. "We won't come close to meeting the needs in the community," says Seattle Lighthouse Deaf-Blind Teaching and Technology Services manager, Amy Koehl. "But this program will let us show the huge need and the way access to technology changes people's lives."

Essentially, the project places specially adapted computer equipment in the homes of selected deaf-blind individuals and monitors the effects on their daily lives. "The first month we received over 20 applications," Amy says. "We have about $160,000 to spend on equipment. That sounds like a lot, but assistive technology is very expensive. At our first meeting to approve equipment for the first three participants, we spent $20,000."

Project applicants are carefully screened. "They need to have the skills necessary for the equipment they are requesting. For example, if a person is just beginning to learn to read braille, they will not receive an $11,000 refreshable braille display for their computer until they have acquired the requisite skill," continues Amy.

Fortunately, deaf-blind people can

gain those necessary skills in our Technology Training Center (TTC). The Center, established by a previous federal appropriation, boasts five adapted training stations and two uniquely qualified instructors. Bruce Visser, deaf-blind due to Usher syndrome, communicates with American Sign Language, and concentrates on teaching computer skills for independent living. Meanwhile, Di Black, also a fluent signer, focuses on teaching work-related computer skills. "Both the TTC and Technology Distribution Program are open to both deaf-blind employees and deaf-bind members of the community at large," Amy adds. "We do give those living in western Washington priority."

Participants in the Technology Distribution Program begin with an evaluation by TTC staff to identify training and equipment needs. "People in the program must have a practical need for the equipment, a clean and safe place for it, and be responsible for maintaining the equipment after the pilot program ends," Amy adds. "They also must commit to reporting back once a month on the ways in which they have been using their equipment and give examples of how access has affected their lives. This will give us the data we need to seek additional funding and to expand the program."

For more information about the Deaf-Blind Technology Distribution Program, contact Amy Koehl at 206-436-2213 TTY, 206-436-2106 voice or email at akoehl@seattlelh.com

LIFE IN THE DARK, QUIET LANE

By Scott M. Stoffel

Editor's Note: Scott and his wife, Sandy are former HKNC students.

It's another cold morning in Arlington. I'm a little sweaty, anyway - probably the only guy down in the Metro tunnel who actually appreciates that rush of December air when a train thunders into the subterranean terminal. Beats me which train it is that just came through. I have to walk down to the other end of the tunnel to where the electronic sign is, or I can't tell one from another.

There's a guy looking my way. Did he say something to me? Maybe it was a friendly, "Good morning." Or maybe it was something more like, "How come you walk like a drunken gooney bird landing on an ice slick at 348 miles per hour?" Well, if it was the former, good morning back at ya, buddy. If it was the latter, I should have you know that I do not walk anything like that; my speed was nowhere near 348 miles per hour! Besides, if these legs worked right, why would I bother using the cane?

Truth is, I don't know what he said and I still wouldn't even if I asked him to repeat it. So I'll just smile and take it as a pleasantry.

Ah, I made it to the light-up sign just in time for the next earthquake. Let's see ... it says "Y," I think. That's the first letter, anyway. The whole thing reads something like "Your Line Has Come In," but "Y" is all I need wrestle out of it.

Sometimes it says "B," which is the

first letter of something like "Be Patient; Your Line Is Coming Soon." Of course, that sign isn't always functional. Occasionally, I am left to take a ride of faith. But I've figured out a foolproof system for determining whether or not I got on the right train: If the train goes up onto the bridge across the river, I've got it made. On the other hand, if it goes to Arlington National Cemetery, I'm really in the bone yard.

That's right - I'm heading into DC. I work for the Federal Aviation Administration (FAA). Sorry if the acronym annoys you. When you work for the FAA, everything is an acronym. For instance, I work on FPT for ASD as part of my PMP to improve the NAS. Does that make any sense to you? Yeah? Then can you explain it to me?

There's not much traffic this early in the morning. Not much light, either. Blows my mind why they call this "C Street," 'cause I can't barely "see" a thing.

I sure wouldn't mind if Dawn decided to cross Independence Avenue a little early today on her way to that top-floor office. Not that my wife lets me ogle other babes, but Dawn's the kind of lady you just can't help gawking at. So call me a perve; I'd sure love to see Dawn's radiant beauty right about now.

Well, Dawn can go ahead and sleep in; I'm not hanging around "No-See Street." My office is over on Maryland Avenue. That's the street between New Jersey and Virginia, I think, but I'm lousy with road directions. Why should I bother memorizing road maps considering I'll never own a legal driver's license?

It's 6:05 by the time I reach the office. I'm not the only early bird. It's surprising how many other folks like to get to work before sweet Dawn even gets a start on her rouge. Some of them seem to know who I am. They're very courteous. I try to be the same. Though I can't entirely shake off a certain glum feeling I get from not being able to talk to them. I wonder if I make them feel uncomfortable? Seems inevitable. I try to don a smile, or at least look distracted, so people don't feel like I am pressuring them to communicate - especially since we don't have too many options on that level. A common sense of good will is enough for me.

Security sure is tight these days. I'm half expecting to come in one morning and be required to go through a strip search. Mom's absolutely right about that "Always wear clean underwear" thing. You just never know.

The ASD (Department of Systems Architecture and Investment Analysis) offices are pretty quiet and orderly. The people here are engineers, computer scientists, and various types of business/administrative specialists - in other words, people with a lot of know-how. You might expect there to be a generous heaping of snobbery among all these intellectuals, but I will tell you that stereotype doesn't fit here. Really, the environment around here is quite friendly.

Again, I start feeling somewhat depressed, while I shuffle down the long hall toward my cubicle. A woman sidesteps into a perpendicular hall to allow me room to pass her in the narrow corridor. I'm not sure who she is but can think of two people who have similar shadows. I'm too chicken to risk getting the name wrong, so I don't say anything. I've found that people react better to silence than to being called the wrong name. Basically, that means I don't talk much. How do you suppose my coworkers interpret my silence?

My cube isn't exactly a luxury suite, but it has everything a general engineer needs, except maybe a kitchenette. I always get the PC up and running first off. That's my bridge to interaction around here. Being an engineer, I have my "Plan B," of course, in the event that my computer crashes and is promptly tossed out a window: right here on the wall is my trusty dry-erase board. Just write down what you want to say with the fat marker, and I'll copy edit it for you. Oops! Sorry, my alter-ego is a novelist/editor, and he follows me to the office sometimes. No, I won't edit your writing - I promise.

But that board is a tedious communication system. E-mail or direct typing are much faster. Which reminds me; I need a second to enlarge the screen text.

I'm online and ready to roll now. No pink slips in the e-mail inbox; I guess that's a good sign. There's a note from the NAS Architecture Co-Lead, just a few comments concerning my latest draft of a terminal navigation implementation step. And here's a file attachment of a technical document someone needs me to review today. Ah, and here's some project guidelines from the boss - she's found a new topic for me to research in the vast realm of the National Airspace System.

Okay, have a seat here at the keyboard, and we can talk for a few minutes. I'm Scott Stoffel. I'm legally blind and deaf and walk like a drunken gooney bird landing on an ice slick. It's great to meet you.

Scott and Sandy

MACHINIST TRAINING FOCUSES ON QUALITY AND SAFETY

Reprinted from HORIZONS, Seattle Lighthouse, Winter 2003

After spending thirty-four years with The Boeing Company, Seattle Lighthouse evaluator/trainer, Art Brockway, now teaches blind and deaf-blind machinists how to make aircraft parts. "During my job interview here, they asked me how I would respond if an employee suggested a new and different way to process a part on a machine," Art recalls. "The answer to that one is easy. The first issue, is it safe? Like any other manufacturing company, safety is our foremost concern."

Proper training is essential for maintaining a safe work environment.

Art and his colleagues in the Lighthouse Education and Training Department have been working hard to create an exemplary program for disabled machinists.

"It's been a real team effort, involving a lot of people. We've built a training structure that realistically represents the needs of the Seattle Lighthouse as well as meets the requirements of Boeing and, on the safety side, OSHA and WISHA (Occupational Safety and Health Administration and Washington Industrial Safety and Health Administration). Boeing's requirements state that we need a robust, documented training program. The fact that we meet Boeing's high standards should tell other potential customers that we can deliver a quality product," Art says.

The first step in creating the training program involved interviewing all sixty-five blind, deaf-blind and sighted employees working on the Boeing contract and establishing a training file for each. Art's interviews covered each machinist's background, current skill sets, past experience and future aspirations. "It was a great opportunity for me to get to know everyone and build relationships, which is critical to my success as a trainer on the floor," he says.

The next phase saw Art working with machine shop staff to document the functions and capabilities of each machine. "We developed a management tool called an Optimum Staffing Chart (OSC)," Art continues. "The OSC lists every machine on the floor and establishes a ratio of set-ups and machinists that need to be trained to run each machine. It establishes the number of hours each month a machinist needs to spend on each machine to maintain their skills."

Every operator in the shop is being certified to run a certain number of machines. Certification is based on the documentation created by the training department. Machinists must pass a formal review of their skills before being certified to operate any given machine. A renewal process states the frequency of skill review necessary to maintain certification. "So far we have created documents and certification processes for sixty-seven machines, including Bridgeport milling machines, slab mills, edgers and punch presses," Art says proudly. "We have another sixty to go."

In addition to receiving instruction directly from Art, some employees are being trained by their co-workers. "We've done a pilot peer training program with our Bridgeport milling machine," Art explains. "Learners and trainers were selected by shop staff. Trainers were certified and then matched with learners. They met for two ninety-minute sessions each week. Training took four to eight weeks depending on individual needs and pace."

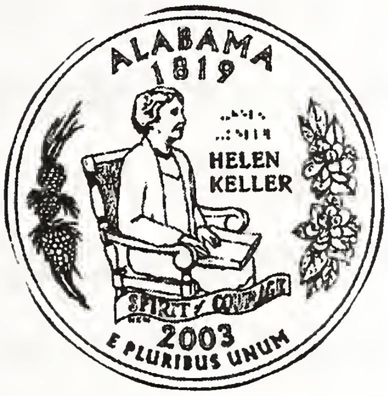
After learners complete peer training, Art conducts an individual skill review. Upon passing their review, each learner becomes certified and is put into the rotation to work on the machine. "They will be guaranteed a minimum number of nours per month on that machine. That orevents erosion of skills and maintains safety on the floor," Art reports.

According to Art, both safety and quality drive this program of rotating vorkers between various machines. "It's not safe, if a person has been trained on a punch press but hasn't run it for a year, to then ask them to do it," he explains.

Art's experience at Boeing as a ull-time instructor and supervisor of quality assurance inspectors prepared nim well for his current position at the Seattle Lighthouse. "Everyone who eceives training needs to receive the same standards and information," he continues. "Here this means preparing information on tape, in Grade One and Grade Two braille and using sign language interpreters." Art meets weekly with Terry Dockter, who coordinates training for deaf-blind machinists. "Terry is deaf and communicates using American Sign Language. He coordinates training for deaf and deaf-blind employees. He also reviews all documents to make sure they meet the needs of deaf-blind machinists."

Art believes the Seattle Lighthouse should capitalize on its highly trained workforce to expand manufacturing operations. "Our employees are the best," he proclaims. "I have tremendous respect for all of them, including support staff and interpreters. We are certified to produce aircraft parts, one of the most complex manufacturing pursuits in the industry. This is a key strength of our organization. We should capitalize on that strength to seek other work opportunities to expand our manufacturing side and create more jobs for blind people."

HERE AND THERE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KELLER
SPIRIT of COURAGE
2003
E PLURIBUS UNUM

In May of this year, the United States Mint issued a commemorative quarter honoring Helen Keller. The coin is available at federal reserve banks and other financial institutions. This is the first time a deaf-blind person has been so honored.

* * * * * * * * * * * *

Going to Las Vegas soon? Valley Braille Service, Inc. of Las Vegas has partnered with Ray Charles Enterprises, Game Makers, Inc., and Bally Gaming Corporation to produce the first slot machines for blind and visually impaired people so that they can play slot machines independently. These machines are called "Ray Charles Tours America" and were recently unveiled at the World Gaming Exposition in Las Vegas. Anyone can play these machines. Players actually interact with a virtual Ray Charles during the play. The prestigious 2002 Access Awards sponsored by the American Foundation for the Blind, was presented to this project. For more information, contact Richard Drosch at (702) 733-6941.

* * * * * * * * * * * *

If you love to cook, you'll love this new service. Now you can receive thousands of recipes by e-mail. Here's how it works: To get a recipe, send an e-mail to recipesatrecipesbyemail.com. Write your search term on the subject line such as "chicken" or "beef ragout." Leave the body of the message blank. When a list of recipes arrives, note the numbers of the recipes you want and send another message with only one selected recipe number on the subject line. Send separate messages for each recipe choice. In a matter of seconds, you'll have results. You can save them or print them in large print or braille, or keep an electronic cookbook of your favorite recipes.

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California Canes has developed a

brand new style of white cane that offers improvements over current models. The company originated the use of carbon fiber materials for more durable and longer lasting canes. Lite Duty Canes for low-vision customers are also available now. For more information or to place an order, call Jeffrey G. Carmer, president and CEO, California Canes at (949) 489-1993.

NAT-CENT NEWS

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EDITORIAL: NEW HORIZONS

By Robert J. Smithdas,
LHD, Litt.d, LHD

In this issue of NAT-CENT NEWS, readers will find several items of special interest that point the way for new developments in providing new accommodations and services for the disabled, including people who are deaf-blind, and pointing up the direction of future progress in overcoming serious problems and limitations caused by disabilities. We live in a fast-paced society now that is constantly looking for improvements in every aspect of living, and there is an ongoing insistence for acceptance of human rights, tolerance, equal opportunities for individuals, and a more realistic understanding of human needs.

Today, many deaf-blind individuals can choose from a growing variety of job opportunities. Many work in competitive employment demonstrating their personal skills and talents. Others are employed as professional workers such as computer programmers and analysts, instructors and teachers. There are a few in other jobs such as a priest, a pastor of an Episcopal group, a lawyer, an owner of a small private company and a veterinarian.

Progress, which basically means "going on and on," has also reached wider areas of providing better living conditions and centers for training of deaf-blind individuals in several different countries since the end of World War II. England now has a second center for assistance to deaf-blind people besides Rainbow Court which was established in the sixties. Germany and Sweden have excellent programs. Here in the United States we have a growing number of start-up programs such as state-run programs, besides the Helen Keller National Center with its comprehensive training program. Canada has a special apartment complex especially adapted for deaf-blind residents and an excellent intervenor system for deaf-blind persons who live alone. And, in Norway, people who are deaf-blind have their own small village.

To my knowledge, there is no complete list of existing centers for serving deaf-blind people in various countries and the sort of services they provide. The descriptions of their services are generally brief and limited in detail - rarely providing information concerning their histories and resources.

It would be a great boon to work for and with the deaf-blind communities if there was a central source of information for all available agencies that provide services, but perhaps the channels for sharing vital information between service providers is still to be developed and integrated.

In retrospect, what has been achieved in the fields of education and rehabilitation of deaf-blind people in the past fifty years is truly remarkable. We are always on the edge of the future, and all signs seem to be indicating that there will be new horizons to explore.

HELEN KELLER NATIONAL CENTER HONORS JOB PROVIDERS

By Dolores Kazanjian

Reprinted from The Port Washington News, June 2003

A lively group of staff, students, guide dogs, and representatives of corporations and community organizations recently gathered at the Helen Keller National Center (HKNC) in Sands Point to recognize the efforts of local employers who have hired students enrolled in HKNC's Vocational Program. The Work Providers Breakfast was held in conjunction with Helen Keller Deaf-Blind Awareness Week and Helen Keller's 123rd birthday.

In his opening remarks, Joseph McNulty, HKNC's executive director, spoke of the substantial progress that has been made in the concept of vocational education for people who are deaf-blind. "Since the late '70's," he said, "we have moved from a sheltered workshop type of situation, where students sat at benches, to where we are today." He added, "We are so proud of our students."

Acknowledging the employers, he said, "Because someone on L.I. took a chance on them (the students), they are leaving here with a work history, a resume. They are leaving here motivated and confident."

McNulty also spoke of the importance of the opportunity for deaf-blind individuals to interact with those who are not, and vice-versa. He commented, "The public has a chance to see them in the way they work on production teams, at the deli, at Starbucks."

Kathy Mezack, coordinator of Vocational Services for HKNC, welcomed the honored guests and students. The Vocational Services Program serves to advance the overall organization's mission of enabling deaf-blind individuals to live and work as independently as possible in their community of choice.

"A special objective of our program," she said, "is to help students to enter and re-enter the work force." The program accomplishes its objectives by providing evaluation, training, job coaches, and placement in community work experience sites to young adults. The ultimate goal is to enable individuals to obtain meaningful work in their home communities.

In welcoming the community work providers, Mezack emphasized the benefits to both student and employer.

The student intern gains experience in "real-life" facilities, develops self-confidence and pride in his or her accomplishments, and feels a sense of belonging. "They develop the ability to earn a paycheck, security and independence," she said. The employer, in turn, gets a skilled, motivated, reliable employee. "They make excellent employees," said Mezack, adding, "the quality of the labor force is a real issue - a key to the bottom line."

Robert Hendrickson, DVM, from the Manhasset Animal Hospital was a keynote speaker on behalf of the employers. One of the students had expressed an interest in working with animals, so the Vocational Services office called the hospital. Dr. Hendrickson said, "When I got a call asking if I would accept a student volunteer, I didn't know what to expect. I met with Theresa and found her to be bright, eager and confident."

Theresa started by walking the dogs that were boarding at the animal hospital. Hendrickson said that she demonstrated, among other skills, the ability to identify animals that were having difficulty and needed attention. Gradually she took on additional responsibilities, including dentistry. "She did so well," Hendrickson said, "that we offered her a paid job."

Having completed her stint at Manhasset Animal Hospital, Theresa has found a permanent job working with animals in her home state of Illinois. "We were all sorry to see her go," said Hendrickson.

Interestingly, Dr. Hendrickson found that Theresa taught him some important lessons. First, he said that he had been in the habit of rushing around throwing out instructions to others. "Theresa taught me to speak slowly and make eye contact," he said, a habit that he now uses to advantage with all his co-workers. He added, "She also taught me that we can connect with animals through feelings."

Ronnie Hall, representing the students, spoke next. Exuding apparently boundless energy, Ronnie spoke of his experience in working at two sites: Central Credit Union in Forest Hills and Five J's Jewelers in Port Washington. He spoke very highly of his employers, specifically Arlene Rudin at the Credit Union and Joan Hutchinson at Five J's.

Ronnie, who studies information technology at HKNC, does general clerical work, filing, accounts payable, loan processing, maintenance of a customer database, and other general office work. "If my boss needs anything done, I do it, and that's pretty much it."

(Editorial note: what boss would not love an employee with that attitude?)

In a subsequent conversation, Rudin said, "Ronnie has done more for me than I can say. He is a terrific worker. The staff are delighted that they (the students) can do the work that the staff may not want to do or have time to do."

(L. To R.) Joan Hutchinson, Ron Hall and Kathy Mezack

Each of the employers in attendance was presented with a beautiful plaque, which had a built in clock. The plaques were handmade by HKNC's vocational students. Mezack also honored the service departments at HKNC who provided work opportunities for the students, including the Kitchen, Maintenance and the Library.

Some of the LI for-profit and not-for-profit work experience providers, in addition to those already mentioned, include Association for the Help of Retarded Children (AHRC). The Gap, Filene's Basement, Big Brothers/Big Sisters, Network Associates, St. Francis Hospital, Wal-Mart, Pizza Hut, T.J. Maxx, Target, Tower Records, Subway, North Shore Animal League, Trunz, Waldbaum's, Jimmy's Shoes and Alpers Hardware.

Afterwards Allison Burrows, from the Community Education Department, offered a tour of the facility. As most of Port News' readers know, the Helen Keller National Center for Deaf-Blind Youths is located on a beautiful 25-acre campus in Sands Point, adjacent to the Sands Point Preserve. For more information on the organization, one can call 516-944-8900, or visit their website at www.hknc.org.

In observing and speaking with the students enrolled in the work experience project, we were struck with their enthusiasm and commitment. Their concern is only to secure regular work that will give them a sense of belonging and being productive, and that will enable them to live independently. It gives pause to those of us who nitpick at our job's every flaw. A former student, Scott Stoffel, summarized his feelings in a poem.

ODE TO THE WORK PROVIDERS

By Scott Stoffel, former
HKNC Student.

For one who roams the work unhindered,
how trifling some things may seem,
but to one bound in chains of iron
the simple things are but a dream.

How truly special it is
when along comes one who holds a key
and casts aside those iron shackles
to set a human spirit free.

HE DOES BRAILLER REPAIRS NATIONWIDE

by Jack Gilson

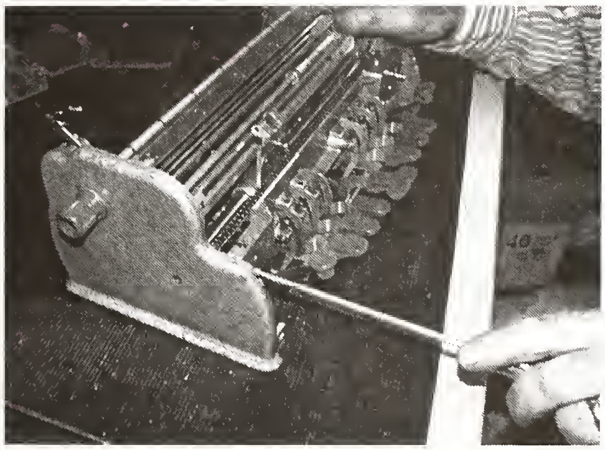
Reprinted from Region 3 Journal,
Volume 1, Issue 3

When you are born deaf, and then go blind later in life, it's kind of like getting the "double whammy" of disabilities. But Atlanta, Georgia resident, Frank L., hasn't let it get in his way too much, nor keep him from ultimately going back to work.

Frank was born in South Africa and moved to the U.S. as an adult. He worked as an auto mechanic until his loss of vision from the progressive eye disease retinitis pigmentosa became too severe. As he came closer to being totally blind, Frank began to learn braille, knowing that it would eventually become his only method of reading.

Two years ago, with the encouragement from his Department of Labor Vocational Rehabilitation counselor, Diane Conley, Frank L. embarked on a new career. He decided to apply his years of mechanical experience and become a repairer of Perkins Braillewriters, the standard braille "typewriter" for people who read and write braille.

The first step to starting this cottage industry was to get training. Susan Lascek, the Southeast U.S. representative of the Helen Keller National Center for Deaf-Blind Adults in New York, arranged for Frank to receive Perkins repair training at their Center. Following this, Dr. Robert Crouse, the executive director of Blind and Low Vision Services of North Georgia in Smyrna, found space and administrative support for Frank's new business at his center.



Frank uses standard tools and hundreds of small parts to repair braillewriters. He keeps the tiny parts in empty styrofoam egg cartons. For his Internet access, DOL's Assistive Work Technology unit recommended special screen reader software to drive a paperless braille display device with mechanical braille dots magically changing to allow him access to the text on the PC screen.

Today, Frank L. is the only Perkins Braillewriter repairperson in Georgia. By advertising at conferences, over the Internet (Frank can be reached at doctorbrailler@bellsouth.net), and through friends, the word has spread about Frank's new carer and business. From a simple cleaning to a major overhaul, "Doctor Brailler" can fix what's wrong with his customers' ailing braillewriters.

Did you Know?

There are 756 parts in a Perkins Brailler, 354 different parts in all, assembled with finer precision than a watch. The Perkins Brailler was developed at the Perkins School for the Blind in the 1930's. WW II prevented the production of the machines until 1951 and there are now more than a quarter of a million machines in circulation worldwide.

THE BROTHERS PROUTY

by Bill Prouty

Reprinted from NEWS FROM ADVOCATES FOR DEAF-BLIND, Winter 2003

My name is Bill. I'm 23, and I have a brother who is deaf-blind and two years my junior. When my mom asked me to write about the experience of having Andrew as a sibling, I wasn't sure what she wanted and I'm still a bit confused. If my attendance at CLF (Children Linking Families) weekends over the last decade has taught me anything, it's that all kids who are deaf-blind are extremely unique, including my brother. So with that caveat in mind, hopefully my thoughts aren't too rambling and may be of some use.

The biggest issue for me growing up with Andrew was communication. Being two years older, I learned to sign just as he did. During our early years I don't think we had many problems. In fact, looking back on a video of us when I was about six, I can't believe how well we got on - although my mom may have stories to the contrary. For reasons I don't recall, at some point around the age of ten, my signing skills began to lag behind the rest of the family.

Looking back I probably understood that I should continue learning new signs, but because I was either stubborn, resentful of the extra work, disinterested or it was just too difficult, my sign language vocabulary hit a plateau. I wanted a brother like my friends who I could play with without using extra energy and concentration simply to tell him what Lego piece I wanted.

I think our communication was poorest when I was at the "cuddly" age of fourteen. I didn't have patience for anyone, especially Andrew. This was aggravated by Andrew giggling when he either didn't understand my substandard signing, was nervous, or simply thought what I said was funny. Unfortunately, struggling to talk with a little brother who is constantly laughing at you is incredibly frustrating - which is why I often gave up and wrote him an angry note or just asked my parents to interpret for me.

I can remember vividly one incident when Andrew broke one of my many prized possessions. Not being able to shout at him like a normal brother, I just slugged him one.

This may have been one of the reasons that my parents thought it was worth going to see a family counselor. Although I can't blame them, they should know the ferocity of my stubbornness better than to try to get me to talk to someone I considered a "worthless shrink." The session lasted less than an hour, and was never repeated again. In all honesty, I really don't think Andrew and I ever had any deep-rooted psychological problems - we were simply embodying our communication frustrations as brothers do.

To Andrew's credit, over the last 21 years he has adapted to my unique sign language "accent," which I doubt many other deaf people would understand. As my patience increased with maturity, I learned to fingerspell words that slipped my mind and ask Andrew to teach me the correct hand sign. Even as my interest in Andrew increased, my opportunities to use new vocabulary diminished as I became caught up in my own busy life and eventually moved away from home to college.

Living in London and not using sign language in over a year has actually allowed me to get to know my brother better than ever before. Through email and AOL Instant Messenger I have had some amazing conversations with Andrew, unencumbered by hand signs or the large time investment normally required to convey a simple idea. I look forward to traveling home over Christmas to see if our positive digital relationship will translate into better face-to-face communication.

Although I doubt I will ever consider myself an adult, the maturity level between Andrew and me is far greater than the two years that separate us physically. Because of the difference in social development, Andrew and I have completely different interests that can make our conversations quite extraordinary.

Last week we discussed terrorism and President Bush's foreign policy in the same breath as Wonder Woman comic books and the latest Super Mario game, although I must admit many of my buddies can still be found behind game consoles from time to time.

Because Andrew takes everything extremely literally and his information is so restricted, sometimes I feel like I am talking to a fundamentalist revolutionary leader. He is very literal. When I was younger I simply didn't grasp how isolated he was, and the reasons he, in turn, couldn't understand where I was coming from. Recently I have begun to get him to challenge his own beliefs and forced him to question the information he gets from the media.

By my estimates, although Andrew is as intelligent as his peers, he is caught in a social time-warp of between 6 to 8 years. Fortunately, he seems to continue to grow and mature in the same ways I did, only at a slower rate. In the last few years he has reached a point where we increasingly share common interests, which partially explains why we got on so much better at the end of our teenage years.

Until I was old enough to understand Andrew's unique situation at the age of about twelve, I may have unwittingly competed with him for attention. Because Andrew's world is so much smaller than my own, when we were younger he looked to me as someone to emulate and learn from. Often times this led to outright imitation, which as any older brother will tell you, is one of the most annoying things any little brother can do. This was probably most acute at extended family gatherings when my little brother upstaged my "far superior" show-off demonstrations. I couldn't understand why my daring acrobatics garnered less attention than my little brother's awkward stumbles.

I don't remember ever competing outright with Andrew, but the constant visits by specialists, teachers, interpreters, doctors and programs administrators may have affected me subconsciously when I was young, although in truth, I have no idea.

Once I recognized the real reasons for the extra attention given to my brother I didn't feel any need to compete. My only occasional frustration was the amount of time he required from my parents when it dug into things I wanted them to do with me. Fortunately, I think they were extremely conscious of this and made every possible attempt to spread their time equally.

Andrew's physical limitations have occasionally been a challenge. At the most egotistical level, when I was younger, I just wanted someone to play baseball with. More broadly, any time our family planned an activity we budgeted twice the necessary amount of time so

Andrew could participate and actually enjoy the experience without being too rushed. His balance and vision negated outright some activities such as family mountain biking trips or visits to a dude ranch. Fortunately, this was never really an issue because my parents would either select a trip that everyone could enjoy, or split up, one taking Liz and me while the other stayed back with Andrew. Disney World was an excellent exception where we all enjoyed "front of the line" passes thanks to Andrew.

Other points of contention while growing up were the numerous special accommodations that took root in our house. I'm sure some of you have already experienced a TTY screech cutting off your voice conversation on the telephone line mid-sentence. Closed captioning seemed novel at first, but can be extremely annoying when it covers the subtitles of a film, or your little brother's head blocks half the screen while he attempts to follow the story. I often got so frustrated when Andrew paused a video halfway through to ask a question or re-read the captions that I gave up and left. It simply wasn't fair that everyone should suffer just for Andrew's benefit. Fortunately, the clunky accommodations of the past are being replaced by slicker solutions. Now when we watch movies, Andrew plugs in a separate monitor that he can press his face up against until he's tan. The TTY is also on a separate line so our sister Liz can talk to all her suitors without getting into fights with Andrew.

Most of the epic battles I had with Andrew when we were younger ignited after he either played with my things without asking or broke some delicate toy that I had invested a lot of time to get just right. It didn't help that I was fairly anal about my stuff, but even had I been a slob, Andrew's sticky "honey hands" would still have led to conflict. Early on I was conditioned to guard my belongings to keep them safe and clean, and only after motorcycling through Morocco have I overcome this minor OCD complex. Whether my petty issue was attributable to Andrew or not, to this day our family still has to remind Andrew to be gentle with the cat and make sure all the honey or jam is cleaned off his hands before he moves to the computer.

My suggestions are fairly straightforward and intuitive. In fact, I'm probably just regurgitating the techniques my parents employed when they raised Andrew and me.

Make communication as easy as possible. Ask your hearing child if he and his friends would like to take sign language classes together. Demonstrate how hearing people outside of your immediate family think sign language is an extremely interesting skill. The more unique and, dare I say "cool," signing appears, the more your child and his friends will want to do it. Present sign language not simply as an obligation, but something that will benefit both siblings equally.

Fairness is important to avoiding resentment. Don't force activities and accommodations on everyone in the family just for your deaf child's benefit. Make sure the same rules apply to everyone. Don't worry too much if your kids fight. Just because they hate each other now doesn't mean they won't appreciate each other later. I think this has less to do with deaf-blindness and more to do with just growing up.

Seize on activities that your child who is deaf-blind and your hearing children can enjoy together. In my family many non-verbal activities such as Legos, video games, and a parade of cats, dogs, rats, lizards, hamsters, fish and birds formed the strongest links I still share with Andrew. The more time siblings spend together of their own election, the more they will communicate and be able to relate.

Looking back, I regret that many of Andrew's memories of me involve conflict, but I hope to make up for lost time in the future. When I was five, Andrew was my best friend. I didn't know or care if he was deaf-blind - he was simply my brother. Although we had some rough times in the subsequent decade, the longer I've spent getting to know him the more I have grown in appreciation. Communication and patience on both our parts has played a major role, but increased maturity has been the main factor helping us relate. With time in our favor, I look forward to learning more about my brother and re-establishing the relationship we had when we were five.

VOLUNTEER SERVICES FOR SENIORS

Reprinted from the Port Washington News, April 2003

Students at the Helen Keller National Center (HKNC) are now offering volunteer services for senior citizens. One of the facilities they provide services to is the Sands Point Center for Health and Rehabilitation.

The volunteers host one-on-one games, puzzles and companionship for many of the residents who may not have any visitors. The volunteers aid residents who have dementia, some of whom are visually and hearing impaired as well.

According to Karen Toback, director of Recreation at the Sands Point Center, "There is nothing more rewarding and enriching than bringing seniors and younger adults together. This sharing of abilities and people relating on various planes caps off what we try to do here."

There are many alternatives to communicating with people who are impaired. Peggy Costello, a speech pathologist at HKNC, states "There are non-symbolic communications such as body movement, facial gestures, physical manipulation, eye gaze, touch and cues. These forms of communication help convey meaning."

If the elderly have difficulty expressing their needs, there are other ways to communicate, such as through eye gaze, vocalization, gesture and pointing and manipulating objects. Many families or caretakers of seniors learn to be more sensitive to their needs. Individuals can encourage these forms of communication.

One approach to encourage identification of others for elderly people is through smell. Aromatherapy is a soothing, calming way to gently stimulate visually or hearing impaired seniors.

There are exciting programs involving fragrances and grooming at HKNC which can be utilized by the elderly, including vibrating scented foot baths, aromatic hand massage and nail care. Tantalizing aromas swirl through the air by small hand held fans, aromatic diffusers or simply by placing a Little Tree Air Freshener in the room. An environment filled with a sense of security and stability can be provided by additional "acts of courtesy" to meet the needs of seniors.

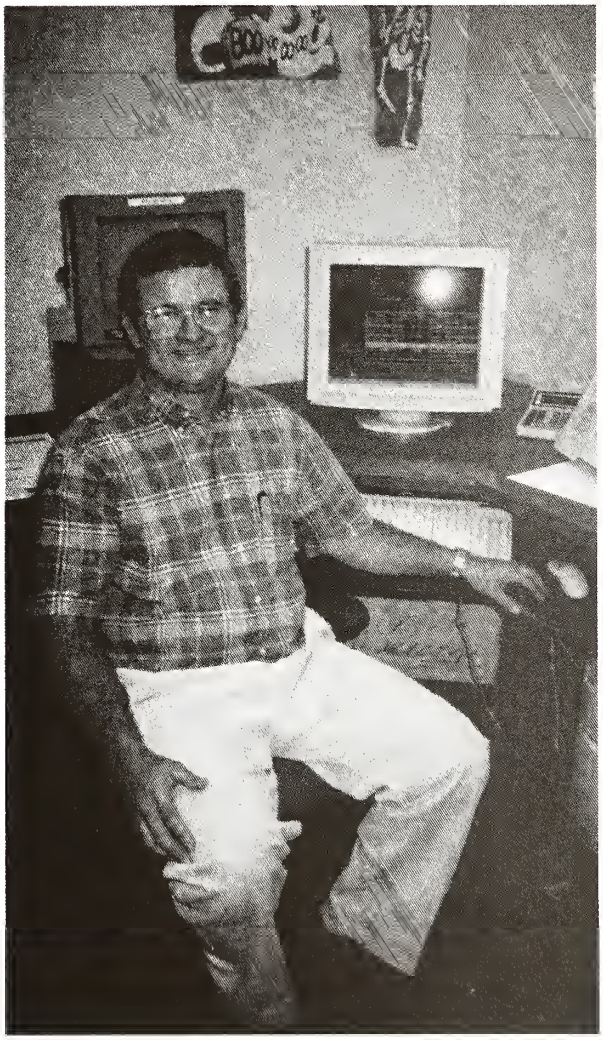
Volunteers, Marcia McDermott and Todd Thompson, who both are deaf-blind, know exactly how to reach and motivate seniors. Marcia communicates to seniors with the use of a communication board. She invites them to choose the activity in which they prefer to participate. Todd Thompson shares the gift of music. He enables the residents to be embraced by his grand piano music for their listening enjoyment, providing auditory stimulation which everyone appreciates.

(L. To R.) HKNC student volunteer, Marcia McDermott shares a joke with HKNC executive director, Joe McNulty.

According to Sister Bernadette Wynne, co-ordinator of the National Training Team at HKNC, "Communication is the most basic need for all persons. There are numerous ways to communicate. It is worth the time to learn how to relate to another person. It requires us to slow down and be comfortable with alternative methods of communication."

SUCCESS IN ANY LANGUAGE

From the Pennsylvania OVR 2002 Annual Report



Richard Putt is an ordinary guy. He owns a home that he helped to build and lives there with his wife and children. He works at Huntingdon County Children's Services as a fiscal assistant.

Richard's supervisor, Robin Simpson, says, "I don't know what I would do without Richard. He has made my job easier. He is an example of someone who accomplished much with his abilities. He inspires us to be the best we can be. We have learned to communicate with each other and other employees have enjoyed learning another language."

Richard is deaf-blind as a result of Ushers syndrome. He received his Associate's Degree in Accounting from Rochester Technical Institute for the Deaf in 1982. He worked for many years as a construction laborer until his vision decreased to the point where he was unable to work safely in the construction field.

Richard applied to the Altoona BBV's Office and initially worked with VR Counselor Alan Curtis to develop an employment plan. Counselor Curtis arranged for Richard to attend the Helen Keller National Center for vocational evaluation, independent living skill training, and trial work experiences.

Upon completion of his training, he returned home and worked with VR Counselors Alan Curtis and Bob Wertz to locate employment. He was provided with job development, job coaching, communication aids, computer access technology, and electronic low vision aids. In addition, a rehabilitation teacher and orientation and mobility instructor followed up with independent living skill training specific to his home and workplace.

"The diverse workplace is one that recognizes and values the qualities of my skills. With a job, you better understand communication and work," Richard says.

MEET JENNÉ ARNOLD: Seattle Lighthouse Employee of the Year - 2002

Reprinted from HORIZONS, Seattle Lighthouse, Spring 2003

2002 WORKER OF THE YEAR
Jenné Arnold

Lighthouse President, George Jacobson, congratulates Jenné

Jenné works as the Rehabilitation Department administrative assistant. As Paula Hoffman, director of Rehabilitation says, "If you know Jenné, you know she is a positive, energetic and fun person with a strong work ethic.

She loves challenges, and loves learning about everything under the sun, including what is needed to enhance her job skills."

Jenné is deaf-blind due to a genetic condition called Usher syndrome. People with Usher syndrome are typically born deaf and with a degenerative eye condition called retinitis pigmentosa (RP). Symptoms of RP typically appear early in life as night blindness and progress with loss of peripheral sight and a continually narrowing tunnel of central vision. Presently, Jenné retains a few degrees of usable vision and foresees becoming totally blind at some point.

"Jenné has consistently accomplished a tremendous amount of high-quality work," Paula continues. Much of her time is spent supporting the Lighthouse's annual Deaf-Blind Retreat. "She handles correspondence, applications, confirmations, data entry, file maintenance and form revisions," Paula explains. "Through the introduction of electronic forms and use of e-mail, Jenné has greatly reduced our mailings and copying needed to support this major national event."

In order to accomplish these tasks successfully, Jenné uses a number of accommodations and supports. She participates in meetings with hearing colleagues by utilizing the Lighthouse's in-house Interpreting Department. On her desk you will find a closed circuit television (CCTV) that magnifies printed materials and provides a wide range of color contrasts to better suit her visual condition. She handles phone calls with a telecommunications device that allows her to type messages to her caller with her computer keyboard.

Before joining the Seattle Lighthouse, Jenné attended the 1997 Deaf-Blind

Retreat herself. Convinced that the Lighthouse was the place for her, she accepted the administrative assistant position in February of 1998.

Growing up in San Diego, she attended the Riverside School for the Deaf. She entered the world of work at the age of sixteen, doing landscaping work at Sea World. Later while attending Gallaudet University in Washington, DC, she came to realize that she was also losing her sight.

After an initial period of denial, Jenné resolved to continue living independently as a deaf-blind person. Jenné is the mother of four children, ranging in age from one to eighteen years. She is a tireless advocate on behalf of the deaf-blind community. Jenné is also an avid football fan.

As The Seattle Lighthouse's Employee

of the Year, she is also our nominee for the National Industries for the Blind (NIB) Milton J. Samuelson Career Achievement Award. This honor is given for leadership in the blindness field to a visually impaired employee working in an indirect labor position for a NIB associated agency. Milton J. Samuelson, who once served as executive director of the Chicago Lighthouse for the Blind, was well known for his efforts to create meaningful employment opportunities for people with visual impairments. As our nominee for this prestigious award, Jenné will represent the Seattle Lighthouse at the NIB National Convention.

Jenné's comments, printed below, were translated by using an American Sign Language interpreter. We spoke to Jenné in English; the interpreter then translated our speech into American Sign Language (ASL) for Jenné. She responded in ASL, and the interpreter translated her comments back to us in spoken English.

American Sign Language is a full, rich, natural language unrelated to English or any other spoken language. ASL is composed of complicated combinations of hand and body movements and specific facial expressions, formulated following a complex grammatical structure.

"One of my past jobs was working as a personnel clerk for the Army's Civilian Personnel Office in Germany. Some of the things I did in that job were very similar to things I do now, here at the Seattle Lighthouse. The main difference is communication. At that job, no one knew sign language. I communicated primarily by writing notes to people. Working in an environment where sign language is not used is extremely limiting. I was not able to participate in meetings, for example. I was given very limited information - just what was required to do my job.

"At the Seattle Lighthouse there are dozens of deaf-blind people using American Sign Language. Many of the hearing staff in the Deaf-Blind Program are fluent signers, and of course we have our Interpreting Department. Here I feel like part of the crowd. I can be involved on all levels. At my old job I couldn't participate in meetings. At the Lighthouse, because of the communication systems that are in place, I can be the facilitator and run our departmental staff meetings when it's my turn. It's a case of an extreme lack of accessibility versus a situation where accessibility is a top priority."

DEAF-BLIND MAN CALLS WAL-MART & STATE UNFAIR

By James Thalman

Deseret Morning News, Utah

A deaf and blind man from West Jordan believes that insensitivity by Wal-Mart workers and inadequate attention by a State disabled training program has cost him a job as a bicycle assembler at the Jordan Landing Wal-Mart.

Stephen Ehrlich is convinced that a simple mis-communication with a fellow worker was blown out of proportion and used as an excuse to end his training, even though the employee told managers it was no big deal, and Ehrlich was exceeding production expectations in the department.

Spokesmen for Wal-Mart and the State will only say that things just didn't work out. Ehrlich has contacted the Disability Law Center and is considering legal action.

"He was not an employee, he was part of a State training program," said Tom Stewart, spokesman at Wal-Mart headquarters in Arkansas. "We have a large number of disabled employees in our stores, and we treat everyone with the utmost respect." Asked if the outcome might have been a bit drastic, considering that the other employee involved did not make an issue of it and that Ehrlich had been told by his boss he was doing a great job, Stewart reiterated that Ehrlich was not an employee and that respect for every individual is a core philosophy at Wal-Mart. Stewart said because Ehrlich was part of a State training program; he couldn't say if Ehrlich could come back.

Using American Sign Language through an interpreter, Ehrlich told the Deseret Morning News he would like nothing more than to go back. He added that going public with his story isn't an attempt to embarrass the State nor the discount chain but to help educate people about the deaf-blind culture.

He believes he was discriminated against and that he knows Wal-Mart could accommodate him because it provides accommodations for a deaf-blind employee at a store in Ohio.

Kevin Duffy, coordinator of Vocational Rehabilitation for the State Division of Services for the Blind and Visually Impaired, is bound by Federal law not to talk publicly about individual cases. But he said the sole reason for the state even having his office is to help people like Ehrlich to obtain and maintain jobs to become successful and independent as possible.

"There is fear sometimes on the part of employers that someone who is disabled might get hurt on the job," Duffy said. "And other employees and the public really aren't sure how to interact with the disabled or even if they should.

"But things have worked out between people with disabilities and with a range of employers. The State doesn't just drop people when things don't go well. We move on and see what else might be out there."

Ehrlich, 55, said he thought he was getting every indication his would be another success story, even though he considered his orientation by Wal-Mart sketchy at best and that the "job coach" the State provided was distracted by a number of personal problems that left Ehrlich in the lurch.

"Despite that, I found true joy in the work and fell in love with the job, and I was trying my best to make things go smoothly," he said. The personnel director at the Wal-Mart gave him a performance pin at the end of his first week and told him that if he collected four pins it would be worth Wal-Mart stock. Better than that, he said, was the sense that he was making it.

That all went sour a week later. Ehrlich said that another assembler, who knew that lightly touching the back of his hand was the least startling way to get Ehrlich's attention, grabbed his shoulders and tried to move him.

"Because a deaf-blind person has no personal alarm system other than touch, being grabbed suddenly will trigger an automatic defense reaction," Ehrlich said. "I didn't push back but moved to protect myself. I was scared and didn't know what to do. I was trying to wave him away and tell him what he was doing was inappropriate."

The co-worker let go and Ehrlich says he just stood still, with his arms folded for about 10 minutes not knowing what was happening. Other employees witnessing the incident apparently took his posture to mean he was angry and shouldn't be bothered.

"He knew there was a better way to interact with me, and other employees did too," Ehrlich said. "But throughout this they were not encouraged to work or interact with me. As far as I could tell, they weren't advised how to alleviate that initial fear of me and so they never felt like the could approach me. I was more than happy to write in block letters on their hands if they had just given me the chance to."

"Sighted and hearing people really don't understand facial expressions among the deaf," said Ehrlich's wife, Jana. "Facial expressions are their voice inflections, and they will often look a lot more agitated than they really are because they're trying to make a point."

"It is called a cultural conflict of communication," Ehrlich said. "The hearing public doesn't feel comfortable with our expressions, and deaf people do not feel comfortable with the hearing public's misjudgment, misinterpretation and overstated opinion of our complex facial expressions." Until someone takes a class in American Sign Language they really can't understand, he added.

Ehrlich has a Master's Degree in Special Education for the Deaf and just finished teaching a short-course on deaf-blind culture at Salt Lake Community College. He was a deaf-blind rehabilitation teacher for three years but could not find steady work in that field. He said although assembling bikes would be considered menial labor by most people, he wanted to try something completely different to develop new job skills.

Always deaf, and completely blind now for 15 years, Ehrlich lives in constant darkness and silence, a condition where most full-sensory people hate to even think of staying for five minutes. As close as most come to having those disabilities is toying with the question: If you had to choose, would you sooner be deaf or blind?

Ehrlich has Usher's syndrome, which combines congenital deafness, no equilibrium and eventual blindness from retinitis pigmentosa. "He was able to see at one time, so he can envision colors and visualize what you're talking about," Jana Ehrlich said. "He has never been one to feel sorry for himself because by most people's standards he is cut off from the world. He's very active and wants to be busy all the time."

"It was only $7.50 an hour during training," Ehrlich said. "But the pay wasn't why I did it. The payoff for me was learning skills and proving to other people that I could do it. That it's not so much about the disability but what's inside. People just weren't able to catch those aspects of it. I'm sorry Wal-Mart missed what I was making available to them."

Anyone wanting more information about people who are deaf-blind, to refer a disabled person for State services or to provide possible work opportunities, call:323-4343;ortollfree 1-800-284-1823.

INTERNATIONAL NEWS

Reprinted from INFAMA

A new National Centre for Deafblindness, operated by Deafblind UK (England), was recently opened in Peterborough. Deafblind people worked alongside the architects to design features which enable them to navigate their way around independently.

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Switzerland has its first ever stamp in braille to commemorate the 100th Anniversary of the Swiss National Association for the Blind. The braille stamp, worth 70 centimes, takes the form of a red square with the braille number 70 in the middle.

* * * * * * * * * * * *

The Russel Hotel in Bognor Regis, West Sussex, UK, has been specially designed to be as user-friendly as possible to blind and visually impaired people. Guests have talking clocks in their rooms, beds for their dog guides and rails along the extra-wide corridors. The 41-room hotel features a textured carpet in the lobby to guide people to the reception area as well as dog-grooming areas.

* * * * * * * * * * * *

Blind visitors to the Egyptian Museum in Cairo are able to touch such treasures as the mask and throne of King Tutankhamen. Others at the museum can listen to a chamber orchestra composed entirely of blind women and dine at an international fast-food restaurant run by deaf staff.

* * * * * * * * * * * *

A Japanese eye doctor at the Kyoto Prefectural University of Medicine has succeeded in restoring the sight of some patients by cultivating an artificial cornea out of membranes taken from their mouths. Eight of the nine patients who lost their eyesight due to illness or injuries to the surface of the cornea recovered their vision.

* * * * * * * * * * * *

ALOHA!

The Deaf-Blind Explorers, Inc., will be hosting a festive trip: "Deaf-Blind Adventures in Hawaii," May 10-22, 2004. The cost will be $2,045 - double occupancy (and $1865 for SSP's.) and includes:

Round Trip Flight from Los Angeles to Honolulu and Maui to Los Angeles

Six nights on Maui

Six nights on Oahu

Transportation on each island

Welcome and Farewell Dinner, Picnic, Daily Breakfast and More Meals

Lei Greeting

Diamond Head Crater

Mt. Haleakala

Snorkle Cruise

Dinner Cruise off Waikiki

Luau on Maui plus Hula Lessons
Insurance
Many more fun activities.

Please note: You are on your own with transportation to and from Los Angeles. If you would like, we can arrange for our travel agents to help you. For those who are from outside the USA and Canada, a special arrangement will be made separately for the insurance and travel arrangements.

A deposit of $350.00 per person is needed by January 21, 2004. Registrations postmarked after that date will not be accepted.

If you would like a registration form or have any questions, please feel free to contact Lynn Jansen at DeafBlindTravel@aol.com or at 531-242-

4171 (voice). You can also go to www.deafblindexplorers.org to sign up.

SPECIAL NOTICE: The Deaf-Blind Explorers are holding a raffle for a trip for two to Hawaii – six nights in Oahu and 6 nights in Maui, including airfare from and to Los Angeles. The cost is 1 ticket for $5.00, 3 tickets for $10.00 and 10 tickets for $25.00. Proceeds will benefit and support the 2003 D-BE Fund. Contact Lynn Jansen for tickets.

ONWARD

By Robert J. Smithdas

Eastward from the morning and
    westward to the night,
I take to life's broad highway in search of
    new delight;

an old dream lost with waking, a new dream in the making,
and in between, unheard, unseen,
a world of hope and promise that stretches out of sight.

If I should ever travel its byways all day long
and find no hidden beauty, no happy burst of song,
I'll know my quest is ended, as first it was intended,
a winding way that day by day
has led me to the joy of life and kept my spirit strong.

NAT-CENT NEWS

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EDITORIAL
PAST AND FUTURE

By Robert J. Smithdas, LHD, Litt.d, LHD

Now that the old year has ended and a new year is beginning, I find myself reviewing the events and accomplishments of the past, wondering how they will affect the progress of the next twelve months. I've been editor of NAT-CENT NEWS since its inception back in 1969 when HKNC first began its work for and with people who are deaf-blind in its temporary headquarters in New Hyde Park, Long Island. I am always impressed by the progress the Center has made in advancing the well-being of its students and opening new horizons for them as creative citizens who use their abilities with confidence and pride.

In this issue of NAT-CENT NEWS, readers will find a wide variety of articles which spotlight the ingenuity of several deaf-blind individuals. One is a young high school student who has a gift for poetic expression; another is about a man who demonstrates exceptional skill in producing scale wooden replicas of cars, trucks, and trains in minute detail. Years ago one rarely read such stories about the achievements of deaf-blind people, but today such stories are becoming common place.

There is no doubt that improvements in education of people who are deaf-blind and in training techniques have contributed greatly to the success stories we read today, and certainly development of new technologies are also broadening areas of communication and information providing opportunities for employment and social integration. Now we are seeing growing numbers of deaf-blind men and women - proud of their independence and personal achievements - gainfully employed members of society.

I think of my late friend Armand Marcotte from upstate New York. He was totally deaf-blind, yet was an expert basketmaker, a professional weaver who made thick, beautifully woven rugs and supported his wife and two children comfortably for years. He used to tell me, "I cannot see or hear, but I am grateful for the gift of life and blessed with skills so I can enjoy it. There is so much I can learn with my hands, and I am still learning. Life is good if you forget your troubles and try new things and keep busy."

Armand is gone for many years, but I cherish his advice and believe in it.

FINDING DOROTHY: A STORY OF SELF-DISCOVERY

By Dorothy Pakula

As told to Nancy O'Donnell

My name is Dorothy Pakula. I was born on August 31, 1924, and am 79 years young. I was born deaf and recently became legally blind. I know I am not the only older person dealing with vision and hearing loss - there are many of us out there and our numbers are growing. The details of our lives may be slightly different, but our circumstances are similar. We are older adults, learning how to live meaningful lives with vision and hearing loss.

I was born in NY City in 1924 to hearing parents. My parents didn't know what to do with a daughter who was profoundly deaf. My mother, in particular, was very hard on me. She insisted that I learn to read lips and speak. Sign language was not an option! She wanted me to be able to live and work in the "hearing world." At the time, this was a common approach with deaf children but it was not an easy one for me. It wasn't until many years later that I realized that my mother had made a good choice for me. Because of my oral background, I have always been very comfortable living in the hearing world.

When I was three, I contracted polio. It did not affect my mobility until much later in life. At the age of 16, I dropped out of high school. I was very frustrated with the educational system and decided that I would be better off in the world of work. I later went back to school to earn my GED (graduate equivalency degree).

In 1944, I married my husband, William. William was also deaf, but raised as a signer. Because of him, I learned to sign. Despite our communication differences, we had a wonderful life together. He worked for many years as a printer for the Daily News, a local NY newspaper.

At the age of 25, I became blind in my right eye due to a hemorrhage of the optic nerve. Luckily, I was able to function very well with the vision in my left eye so my life basically remained unchanged.

Our only child, Isaac, was born in 1945. He was also deaf. As my mother did with me, I chose to raise him in the hearing world. Although his education started in Junior High School 47 for the Deaf, we later mainstreamed him to a nearby public school. He was the first deaf student mainstreamed in NY City! Isaac was accompanied in the mainstream program by six young girls who were hard of hearing. Times were changing in the Bronx! In the 6th grade, he was fully mainstreamed in a junior high school in the Bronx and was reading above grade level.

While Isaac was young, I was very active in politics and social activities in both deaf and hearing organizations. I was the den mother for my son's Cub Scout troop, and an active supporter of my son's little league team. Throughout my son's early years, I held various jobs within the school system, first as a school aide in the lunch room, then as a teacher's aide in the infant program. My next job was as a paraprofessional in a special education program, working with children with mental retardation, autism and deafness and assisting in the infant program. I even became the shop steward for hearing teachers in Jr. HS 47!

Despite my vision problem, I was still able to run the household, work and have a happy and full life with my son and husband. William was my biggest supporter! He drove me around town, encouraged me to work and, eventually, convinced me to go back to school.

I was the first deaf student at LaGuardia Community College in NY. There were NO interpreting services for deaf college students at that time. Yet, I graduated from LaGuardia with a GPA 3.56 at the age of 46. I transferred to Empire State College and, at the age of 51, received my B.S. in Education for

Deaf Adults. I was later honored by LaGuardia Community College when they named their library for deaf adults after me.

My wonderful husband, William, died in 1991 after suffering many medical problems. We had been married for 47 ½ years! By this time, my son had graduated from college and was teaching.

Luckily, I was working at LaGuardia Community College as the coordinator of Student Support Services. I established the first GED program for deaf adults there. My job kept me busy and helped me to get over my grief. I remained active in the deaf community and even ventured into a new relationship with a lovely man.

One spring day in 2003, I was home by myself, doing things around the house. I was having trouble seeing through my dirty glasses so I took them off to wipe them. I looked up at the light to see where the smudges were. Suddenly, all I could see was a black spot in the middle of my field of vision. What was wrong? I made an emergency appointment with my regular eye specialist for the following day. The doctor immediately knew what had happened, but held off telling me until I saw a retinal specialist.

Two days later, I was in the specialist's office, with an interpreter. He took pictures of my eye and, after carefully looking them over, he told me I had a hemorrhage in the back of my eye. I thought I might have a detached retina but that was not the case. After several other appointments with doctors, the diagnosis was made clear.

I had age-related macular

degeneration (AMD) and there was no cure! I was completely shocked by this horrible news. I didn't know why this had happened to me! At the age of 79, macular degeneration had suddenly and unexpectedly robbed me of my vision. What would I do? How would I read - my passion all my life? How would I do my bills, go grocery shopping, cook or clean my apartment? Simple tasks had become impossible. Everything I loved to do had turned into a huge frustration.

It's hard to describe my feelings at this point in my life. For months, I grieved. I cried. I was depressed! I felt that God was punishing me for something I had done. I became angry with God. I couldn't understand WHY this had happened. I didn't know who I was! I was no longer "Dorothy," an independent and active woman. Now, I was deaf and blind too! I lost all hope and gave up the will to live.

At this time, my son Isaac was living in North Carolina with his wife, Randi. Through a friend who was herself deaf and legally blind, Isaac found out about a training center that could possibly help me. It was the Helen Keller National Center in Sands Point, NY. Isaac drove to NY and the two of us showed up at the Center's doorstep without an appointment in desperation! The staff accommodated us and called Michael Brennan to come to our assistance.

Michael was the HKNC representative for NY state and a deaf-blind man himself from Usher syndrome. He was so helpful! He brought me up to his office, sat me down and started to communicate with me. As you might imagine, I was still emotionally distraught. Yet, Michael patiently waited until I eventually was able to explain my situation. (I didn't know that he was also a certified therapist.) He suggested that I come back for a few counseling sessions. I refused because I had never been to a deaf counselor before. (Did I mention that I can be stubborn?? [smile])

I finally agreed to come for three or four counseling sessions with Michael. He also arranged for a teacher to come to my house to evaluate my training needs. He then referred me to a low vision doctor for an evaluation of my remaining vision. Eventually, this team of professionals recommended that I would benefit from becoming a part-time student at HKNC.

Six months after I was diagnosed with macular degeneration, I became a student at HKNC. November 18th was my first day. You might think that I would be thrilled with this new opportunity, but unfortunately I was still grieving and therefore reluctant to be at the Center. As I sat with Michael, he showed me a device that looked like a TV screen with a movable base. He placed a page of a book on the base and, like magic, the print was magnified onto the screen in a size I could easily see. I soon realized that I would be able to read again!!! I was THRILLED!!! He then showed me a large print TTY, the telephone communication device used by people who are deaf. With the large print display, I could see the text! HOW WONDERFUL!!!

Over the next few days and weeks, I had experiences like this in each department at the Center. The Independent Living Department showed me how to label things in my kitchen and organize my personal items. They determined that cooking on a stove was not safe for me, so they showed me how to use a microwave, an electric skillet and the George Forman grill.

The Technology Department introduced me to computers. The Orientation and Mobility Department determined whether I was traveling the campus safely. At night, in the Residence Building, I met other students, made some friends and even started to mentor some of the younger students, which I love to do. I felt the "old" Dorothy starting to return and it felt great!

In the meantime, the doctors had started me on Visudyne therapy for my AMD. Visudyne is a drug injected into the blood stream that can help to slow the progress of AMD. I am hopeful that this therapy will help me to at least maintain the vision that I still have.

Initially, I had refused to consider learning tactile sign because I thought I wouldn't need it. I could still see well enough to sign visually. Why would I need to learn this?

While living on the HKNC campus, I met many students, some of whom were totally blind and used ASL. They communicated easily by signing into each others' hands. They seemed to be enjoying themselves using this method of communication! I started to realize that I might, at some time in the future, lose more vision and I should be prepared! Now was not the time to be stubborn. I could learn tactile sign while I still had vision and be ready for the future, no matter what happened. I decided to give it a try.

My tactile sign teacher was deaf-blind and uses tactile sign herself, so she knew how I felt. During our first tactile sign class, she suggested I use a blindfold. I WAS TERRIFIED!! Everything was BLACK! Suddenly, I was "blind." It was frightening to me, but my teacher was very patient. She gently took both of my hands in hers and slowly fingerspelled "OK" into my hands. In my panic, I didn't understand her. But I took a deep breath and said, "Dorothy, you can do this!" I slowly felt her start to fingerspell again. My hands followed the shape of hers until I realized that she was making an "O." The next letter was a little more difficult. When my teacher noticed that I was still frustrated, she took the palm of my hand in hers and printed the letter "K" into my palm with her index finger.

Then she fingerspelled it again. SUCCESS! I had figured out my first message tactually!

My teacher then signed the two-handed sign "try." I had no idea what she was trying to tell me. Again, patiently, she printed the letters in my palm. "T-R-Y." Then she made the sign again, while my hands followed hers. I got it! We practiced in this manner for about 10 minutes until I asked if I could take the blindfold off. I had had enough practice for one day.

Next, I decided it was time to learn braille, in case I become blind in the future. REMEMBER, reading is my first love! I need to read like I need to breathe and eat!

Learning braille was difficult for me, but my teachers were all so patient. In the first 10 minutes of my initial braille class, I learned 6 letters, visually and tactually. I have become a motivated student and I bring braille home to practice.

One day, my case manager told me that my training at HK would soon be over. I was SHOCKED! I couldn't believe it - I still had so much to learn! I was really enjoying my time at HKNC. I felt the old depression creep back into my heart. I cried for three days.

After talking with several staff, I decided not to give up hope. I spoke with Angela, my case manager, about extending my training for another month or two. We discussed my goals and what I still needed to learn.

In order to live as independently as possible, I needed a color CCTV in my home. This would allow me to read my mail, pay my bills, correspond with family and friends and stay up-to-date with current events in the newspaper. Angela explained that these decisions would be up to my state counselor who was sponsoring my training. The next case conference would be an important one for me! I tried to put my fears aside and focus on a positive outcome. I put all my energy into learning all I could in my remaining time at HKNC.

In anticipation of my HKNC program coming to an end, I needed to think ahead to where I would live and how I would fill my days when my training was completed. I had started to see my apartment with new eyes. I realized that it was outdated and cluttered, even unsafe! I had to walk up six steps. With my limited vision and unsteady gait, I now realized that this was not where I wanted to be.

I decided that I would like to move to the Port Washington area, to be near the Center. This would allow me to become a volunteer at HK, helping staff with their sign language and students with their programs. My plans were changed when I learned that the rent for an apartment in Port Washington would be about $1600 a month. There was no way I could afford this. Time to go back to the drawing board and figure out "plan B" for new living arrangements.

Meanwhile, the time had finally come for my case conference with my state counselor. Each of the staff who worked with me would report on my progress. The counselor would then decide whether I would get a CCTV and would also tell me how much longer I could stay at the Center as a student. We would discuss living options and my dream to become a volunteer.

SUCCESS!! My counselor reported that the state agreed to purchase a CCTV for me. They would be ordering a "Merlin" color CCTV, the exact machine I had hoped for. I was so happy when I heard this news! Everything was coming together. All of my teachers had positive reports about my progress. I would be finishing my program in about a month. We also discussed my desire to move closer to the Center and to become a volunteer.

I made an appointment with Vera, the head of the Volunteer Department and we discussed different options for me when I finished my training. Together, we figured out a plan that was perfect! I would split my volunteer time between clerical work, teaching sign language to staff and working with a student on basic office work. Things were really falling into place.

However, in the back of my head, I was starting to get worried about my living situation. If I couldn't stay in my current apartment, and couldn't afford to move to Port Washington, what would I do? My teachers told me to "trust" and wait for an answer.

It soon came in the form of an e-mail from my son and daughter-in-law in North Carolina. It said: "We found a nice two-bedroom apartment (near us), bright with big rooms. It has a nice, roomy kitchen and living room and is very convenient to many things! There are four other deaf and deaf-blind residents in that building. It is close to us, the mall and the Wilson Regional Resource Center. You can visit your friends, the hospital, doctors' offices, post office or whatever. The rent is very reasonable and includes heat, water, sewage, appliances, and garbage pickup. There are dead bolts, storm windows and storm doors, a swimming pool, laundry room and a yard in back of the apartments. The landlady is very nice, she can sign since she used to work at a school for the deaf years ago. We feel it is perfect for you so you won't be lonesome - you will see more of us, be with us during the holidays and we will make sure that you are okay. If you need us to do anything for you, we will."

After reading the e-mail, I felt a tremendous weight come off my shoulders. The staff was right. All I had to do was wait and the right opportunity would come along! My son and his wife want me to move near them in North Carolina - and I'm going to do it! This is a wonderful opportunity for me. I will have a brand new apartment, be near my family and be able to have an independent and fulfilling life in NC. WOWOW!!

When I first lost my vision, all I wanted was to get my old life back and become the "old Dorothy." What I now realize is that the "old Dorothy" is gone, and that's OK. I am now the NEW AND IMPROVED Dorothy, ready to step into a life full of promise and exciting opportunities. Because of my training at HKNC, I am ready to start a new adventure in North Carolina. I am so happy because I will be near my children, grandchildren and great grandson and will be able to see them often, especially for the holidays.

In closing, I would like to share my version of one of my favorite poems with you. It is called, "We Know Better, All Women are One." My additions are in parentheses.

I am a woman like you are
I am a mother like you are
I am a worker like you are
(I am an independent lady like you are.
I am a volunteer like you are.)
I am an inamorata like you are
Yet because you live there
And I live here
Or because your appearance or lifestyle is different from mine
People tell us we are not alike
But we can see the differences
In each others' beliefs because our intrinsic ideals are the same
People tell us we are not alike but
We know better
We are all one

DETERMINED CAMPAIGNER

By Tammy J. Oseid

Reprinted from Twin Cities

Pioneer Press, MN

October 2004

Like a lot of aspiring local politicians, Rachel Eggert hasn't won her first few races. Unlike any others in Minnesota and perhaps the nation, the 23-year-old is deaf and legally blind. Still, Eggert beat three other candidates in September's Inver Grove Heights City Council primary. She didn't make the cut for the general election but plans to make a second run for the Inver Grove Heights school board next year.

"I want to keep going on until I win," said Eggert, an Inver Hills Community College student, student senator and self-described freelance campaigner. "I won't give up."

Though technology has helped deaf-blind people across the nation become far more independent, Allison Burrows, from the Helen Keller National Center in New York, says she isn't aware of any who have run for political office. The Center helps people who are deaf-blind find ways to work in fields that interest them. "Good heavens," she said. "I do think that's rather rare."

Door knocking, community parades and other traditional campaigning methods are more difficult when you can't drive, hear or fully see. But Eggert's fingers fly across her Sidekick keyboard to communicate instantly via e-mail or text message. Her face radiates her emotions, especially her passion for politics. She can read lips a little and speak a few words, but sign language is her primary method of communication.

Even after three strikes in local races, the budding politician isn't anywhere close to out. "Every time I run, I get better results, but I need more work," she said.

Overcoming obstacles is one of Eggert's greatest strengths, supporters say. "I am impressed with her determination," said Jessica Eggert, Rachel's older sister, who is also deaf and a Metro State University student majoring in criminal justice. "She is going to try again and not give up."

Rachel and Jessica both have Usher syndrome, a relatively rare condition they inherited from their hearing parents who passed along the recessive gene for the syndrome. About four babies in every 100,000 have the syndrome, which causes deafness and progressive blindness. Their three brothers have normal hearing and sight; all learned sign language to communicate with their sisters.

Jessica Eggert helped her younger sister become independent, showing her how to travel across the metro area via mass transit, showing her how to use cell-phone text-messaging technology to communicate with hearing and non-hearing friends and other means to be independent.

Until Rachel Eggert can file for her next local race, the Inver Hills Community College student and Simley High grad is honing her skills by working on state and national campaigns.

As a 15-year-old, Rachel Eggert started working on Paul Wellstone's 1996 campaign for re-election to the U.S. Senate. Bitten by the political bug, she continued to work on races, including Wellstone's 2002 bid, cut short by his death two years ago.

She hasn't fared so well personally, losing three straight races for Inver Grove Heights city council and school board. This year, she took fifth place with 8 percent of the vote in the Inver Grove Heights city council primary. Of the eight candidates, only four advanced. In 2003, she took 27 percent of the vote in a two-person school board race against incumbent member John Honchell. In 2002, she finished eighth in the primary.

Rachel Eggert envisions a political future broader than Inver Grove Heights. She'd like to make her way to the Capitol. (Rep. Torrey Westrom, R-Elbow Lake, is the only disabled Minnesota legislator. He was blinded during a car accident when he was 14.)

"I want to show that people with disabilities can do anything that normal people think they can't," she said. "I want to see more people look at people with disabilities and see they are the same as everyone."

www.freewebs.com/citizens4eggert

HUG FOR CHARLES FROM DEAF-BLIND BOY

By Laura Elston, Deputy Court Correspondent, PA News in Jordan

Reprinted from The Scotsman, Edinburgh, Scotland October 2004

Deaf and blind youngster, Mohammed Maher, hugged the Prince of Wales close, holding his hand tightly and reaching up to touch the hair on the back of his head. The inquisitive 12-year-old was determined to find out as much as he could about Charles using his sense of touch.

The Prince met Mohammed in Jordan’s former capital city, Salt, while visiting the Stride Centre, a training program for teachers of deaf children. A smiling Charles put his arms around the boy’s shoulder and let him reach up and place his hands on his chest. Holding the Prince’s hand, Mohammed gently placed his cheek on the back of his palm to feel the texture of the heir to the throne’s skin.

Mohammed and his family are Palestinian refugees who live in the Wahdaat camp in Amman, one of many refugee bases in Jordan which borders

Israel. There is an estimated 1.5 million Palestinian and other refugees living in the country - 270,000 of whom live in the 13 camps.

For three years, Mohammed has attended Holy Land Institute for the Deaf school in Salt, which opened in 1964 and was the first place in Jordan to offer education to disabled children. The school, which has 150 students aged between seven to 20, also runs the Stride Centre.

Mohammed, who stays at the school during the week and goes home to his parents on weekends, is now learning sign language. Elizabeth Hume, originally from London, who works at the Centre, said, "When he first came here he was hyper and nervous. He didn't know what was going on. But we gave him a routine and he settled down. He can sign sentences of six words now. We use objects of reference to teach him. He will pick up a cup, feel it and then will place his hands into the sign for drink. He understands the concept of language. He's highly intelligent and has a good sense of humor."

Mohammed, who wears a hearing aid but still has very little hearing, was born deaf and blind. Other students at the school give people names depending on their distinguishing features or appearance. The sign they created for Charles was a double flicking of one ear.

The Stride Centre, which is being renovated, was formerly Jordan's first ever hospital which was built in the 1860's by English missionaries who lived in caves on the hillside. Matthew Hanning, of the Christian Blind Mission who works with the Holy Land Institute, said, "There's still a lot of awareness problems for children with disabilities in Jordan. There's a stigma, but gradually things are changing through organizations like this. "

Brother Andrew of the Anglican Church, who runs the charity-funded Holy Institute, showed the Prince around the Stride Centre. From a balcony, they looked out over the steep city hillsides at the crumbling yellow brick traditional Middle Eastern homes including a large jaded house off the main street which used to be a palace. Parts of Salt are being restored after falling into disrepair when Amman took over as the capital of Jordan. The Prince also watched youngsters sing a song using sign language.

DEAFBLIND MAN TOPS SPEED RECORD

From the newsroom of the BBC,
London, England
August 2004

Graham Hicks smashed his own 104 mph record on a custom built quad bike, by hitting a top speed of 133 mph in front of 100 people in Lincolnshire.

Mr. Graham, who is deaf-blind, said "It just goes to show that given the right support, people with disabilities can compete equally to set a Guinness world record."

Mr Hicks was given the 2004 Variety Award for Outstanding Courage.

He was helped in his ride by a passenger, Brian Sharman, who gave him steering directions through touch.

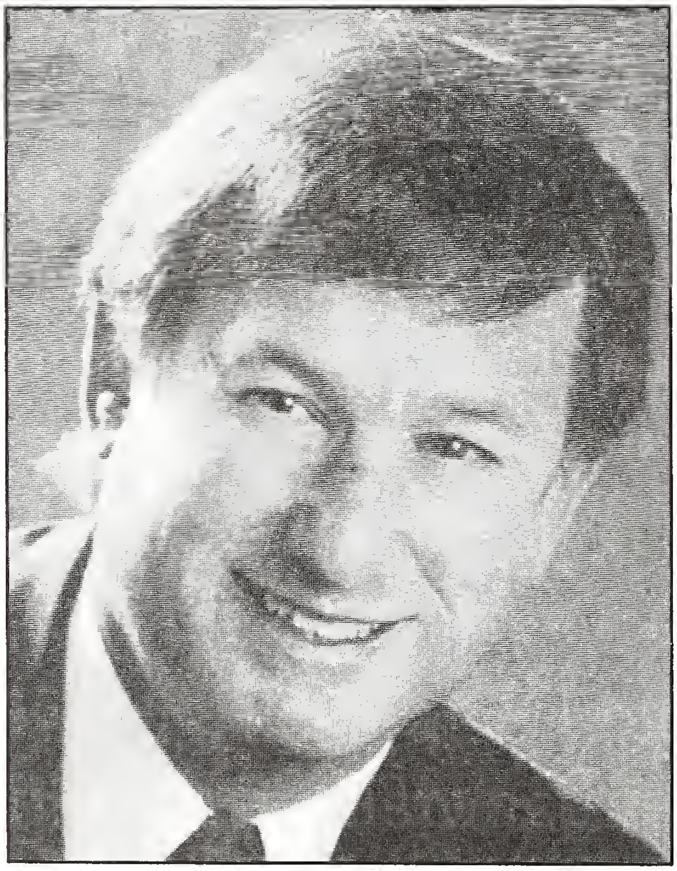
Mr Hicks also holds the record for the greatest distance travelled on a jetski within six hours, racing from Norfolk to Holland in June 2003.

INSPIRING OTHERS TO EMBRACE LIFE'S CHALLENGES

By Claire Curry

Reprinted from NY Newsday

September 2004



Mitchell Shapiro believes that your greatest weakness is your greatest strength. According to friend Karen Perry, this credo propels him forward and is what motivates him to help others in many different ways.

Shapiro is volunteer president of the Long Island affiliate of the Foundation Fighting Blindness, a national organization he's been associated with for the past nine years. He is also the creator of two popular fundraisers. The "Blind" Wine Tasting Gala is an annual fall even that has raised nearly one million dollars for research since its debut nine years ago. The "Blind" Tug-a-Jet Challenge, launched in 2000, is a team competition that also generates revenue and increases awareness. "He inspires hundreds of volunteers and thousands of participants to give of themselves and has raised nearly $1 million for blindness research," Perry says. "As a pro-bono inspirational speaker, he spreads messages of strength, courage and positive attitude at schools, colleges and diverse organizations." This spring, Shapiro founded The Foundation for Sight and Sound, an organization dedicated to enhancing the quality of life for individuals affected by visual and auditory impairments.

Personal experience is what drives Shapiro to encourage those around him. For years, he has faced head on the affects of Usher syndrome, a degenerative disease that results in vision and hearing loss. "Mitch is indefatigable in his mission and stalwart in his resolve that 'it's not about what you don't have,'" Perry says. "Corny jokes and home-baked banana bread are his trademarks and his 'no quit' attitude brings him golfing, deep-sea fishing, traveling, hiking and to many other challenges where those with full sight might not even venture."

Shapiro, from Smithtown, Long Island, sits on Verizon's Citizen's Advisory Panel and has served as a judge, keynote speaker and advisor for numerous events and organizations, including the Nassau County Office of the Physically Challenged. He is the recipient of the Advocacy Award from Suffolk Independent Living Organization and the Outstanding Volunteer of the Year Award from the Association of Fundraising Professionals. He is also active in several business organizations, including the Long Island Association, Public Relations Professionals of Long Island and the International Association of Business Communicators. For more than 20 years, Shapiro enjoyed a successful career as operations manager of the Swan Club Restaurant on Long Island.

DEAF, MUTE, BLIND WOMAN VOTES FOR FIRST TIME AT 90

Reprinted from the Daily Press,
Hampton Roads, Virginia
November 2004

After all these years, Helen Foy finally had her political say. The 90-year-old Hampton woman was among the throng of new voters who helped sway the election Tuesday. Being a first-time voter at her age is story enough, but there's more: Foy is blind, deaf and mute. "You've heard of Helen Keller?" said Henry Thomas Smith, Foy's son. "Well, this is Helen Foy."

I met Foy and her son Monday at her apartment, which she's had for 15 years. Smith said Foy still got around well and remained self-sufficient. She's never worked but can cook, clean and bathe - skills she picked up from family members.

Smith, divorced with no children, lives with Foy because she's up in age, he said. He makes sure she eats before he starts his afternoon shift at the Newport News shipyard.

I was a little skeptical at first. I wondered how Foy would communicate directly with me, let alone cast informed votes in one of the most hotly contested elections. She sat on her couch and appeared asleep. Actually, she was. "She says she dreams about seeing her family," Smith said.

As I greeted her, the petite silver-haired woman clutched my hand like a loving grandmother, turned toward me and smiled broadly behind her shaded glasses. Smith grabbed a newspaper, put her hand on it and then made hand signs in her palm, while saying aloud that I wanted to ask her some questions. She nodded. "She said she just wanted to vote because maybe she can make a difference," Smith interpreted. Later, she would blow me a goodbye kiss.

Foy is from Jacksonville, NC. One of seven children, she was born deaf. Cataracts took her sight later, at 16. Her youngest sister was also deaf. Foy stopped attending school in fifth grade, when her parents died. She developed a personal sign language, which she would later teach her son.

Foy came to Newport News in 1949 with her family. She gave birth to Smith and a daughter but never married their father, who was also deaf and blind. Smith said life was rough and lonely for his mother. The family was ashamed of her because of the disability. It cast her aside, he said. This contributed to why she never voted, even after passage of the Voting Rights Act of 1965. She was embarrassed to be out in public, Smith said. "In her life," he said, "all she has wanted is peace."

Smith, who first voted in the 1992 presidential election, said he asked Foy to vote then. He pressed the issue this year because of the magnitude of the presidential election. He gave her his spin on the candidates - Republican President Bush put the troops in Iraq; Democratic Sen. John Kerry would get them out.

The National Organization on Disability estimates 40 million disabled people are of voting age. In 2000, about 41 percent of disabled voters went to the polls. The number was expected to spike because of the intense interest in this presidential election and the 2002 passage of the Help America Vote Act. The act aims to increase access to polling places and also improve voter technology for the disabled. Hampton uses optical-scan ballots, which require a voter to have sight.

Machines for the disabled are expected next year, said Theresa R. Kyle, Hampton's voting registrar. Virginia allows a disabled voter to receive help at the polls. The ballot could be brought to the voter's vehicle, or someone can assist them in the booth, which is what Smith did.

Foy used sign language to tell Smith her choice, and he was to record the vote exactly that way. "Basically, it's the honor system," Kyle said. It's also illegal for Smith to divulge Foy's vote, Kyle said.

So unless you can communicate directly with Foy, you'll never know.

"After we were done, she just clapped her hands together and smiled," Smith said.

DEAFBLIND STAR TO ADDRESS SUMMIT

By Dan Webber

Reprinted from HEALTH

Harrogate, London, England

Thirty-one year old Amanda Schofield spoke out at the Acquired Deafblindness Network conference hosted by the deafblind charity, Sense, in November, 2004. A Bradford woman who has overcome a rare medical condition to become a successful sportswoman, Amanda addressed medical experts from around the world.

More than 100 delegates from around the globe, including experts in the field, attended the event alongside HRH The Princess Royal, patron of Sense.

This year's conference, entitled "Expectations, Opportunities and Possibilities," heard Amanda talk about her achievements as a national equestrian dressage champion and the many possibilities which exist for deafblind people.

Amanda has won the national dressage championships for the last three years and now hopes to secure sponsorship to allow her to represent Britain at the 2008 Paralympics in Beijing. Each day she makes the journey from her home in Queensbury, Bradford, to nearby Bingley where she trains at the St Ives Equestrian Centre.

Amanda lost her sight when she was a baby before losing her hearing over the course of several years as she was growing up. She communicates using a combination of speech and the manual alphabet and is also proficient in braille. "I was first introduced to riding through Bradford Council's Guide Support Scheme which enabled me to take part in a taster day for riding for disabled people," she said. "I loved it and in 2002 I started a course in equestrian studies at Craven College in Skipton. This summer I got my Btech in horse care and horse management.

"My real ambition is to be part of the country's Paralympic team in Beijing but, in order to take part, I desperately need sponsorship. At the moment I can't afford to take my own horse to competitions so I have to compete on a horse I don't know. This is very difficult as dressage is such a disciplined sport.

"I love my sport and hope I can be a positive role model for other deafblind people. I'm really proud of my achievements so far in life. I hope a company or sponsor is able to help me become the first Yorkshire Paralympic dressage champion."

The Acquired Deafblindness Network is a network of professionals from different countries all working in the field of acquired deafblindness. It was established in 1989 and is recognized by Deafblind International.

Acquired deafblindness is a term used to describe people who have developed both sight and hearing impairments later in life, as opposed to being born deaf and blind. This may be as a result of ageing or due to a genetic condition, accident or illness.

The national deafblind charity, Sense, is a member of the Acquired Deafblindness Network. Sense supports and campaigns for children and adults who are deafblind. It provides specialist information, advice and services to deafblind individuals, their families, caregivers and professionals who work with them. Sense also supports people who have sensory impairments and additional disabilities. For more information on deafblindness visit www.sense.org.uk.

To sponsor Amanda Schofield contact Margaret Hird on 01274 435001 or email: margaret.hird@bradford.gov.uk.

MAN CONQUERS VISION LOSS TO CREATE WOODEN MODELS

Reprinted from The Detroit News,
Detroit, Michigan, October 2004

Every day for the past 15 years, Harold Riley has worked 16-hour days in a small workshop in the basement of his home, creating scale models of antique automobiles and trains that sell for hundreds of dollars throughout the state. And for the past 15 years, Riley has never seen one of his finished products. "I don't think of myself as more special than anyone else who is deaf and blind," Riley explained through the help of his wife and interpreter, Donna. "This is who I am, and making toys is what I do."

Riley, 62, acknowledged that he has

never heard the excited hum of one of his four table saws as he gets ready to create yet another of his more than 25 wooden designs. He admitted he's never seen his finished antique fire truck, complete with an extendable ladder, or his 1930 Ford Coupe with convertible top. But he knows they're right. "There's no mistakes with these," he signed excitedly on the top of his wife's right hand. "They're perfect because I remember."

Riley, who has been deaf since birth, was also born with Usher syndrome, a rare degenerative neurological disease that affects the hearing and vision of more than 10,000 victims in the United States, or 3 - 6 percent of all hearing impaired children in the United States.

But because vision loss with Usher syndrome is degenerative due to retinitis pigmentosa, Riley was able to live a full life in Durand, working as a press welder at F & E Manufacturing in Corunna for 28 years. And in 1989, when Riley lost his vision completely, that did not stop him. "They call me the most profitable guy they had over there," Riley signed with a big grin. "Even when I couldn't see and the company was closing (in 1991), I was the last person they let go."

"Harold was the last worker there when F & E's doors were locked," Donna Riley said with a smile. "That says something about his character."

Before Riley became blind, he spent his spare time constructing wooden replicas of antique automobiles, airplanes and trains. Most designs range from 6-10 inches and sell for as little as $30 or for more than $200. Riley would go to hobby shops across the state, locate a die cast model and reproduce a scale wooden version of the machine within weeks. "He works a lot slower now," Donna Riley explained as she led the way to her husband's workshop in the basement. "The models he did before, he remembers. But when someone requests a new one or he wants to try something out, it will be months before he will think it's correct. It's the perfectionist in him."

As his wife signed to him her explanation of Riley's working environment, a grin started to spread across her husband's youthful face. "I have thrown out so many versions of my designs," he signed, laughing. "Even though I can't see them, I can feel them. I know when they aren't right. I won't keep something that isn't right."

"I tried to help him once," Donna Riley said, smiling. "But I was fired pretty quick. I wasn't doing the wheels right."

Riley has even been asked by the Michigan International Speedway, through the help of Self Help for Independency in Michigan Equalizing the Deaf Blind, to re-create a pace car for the raceway. "The stuff he makes is just amazing," said Jeff Smith, vice president of the organization. "Harold is truly an inspiration."

POEM: ME

By Carlie Grippi

Editor's note: Carlie Grippi is a seventeen year old student at Ohio State School for the Blind. She is legally deaf-blind and a former student at the Helen Keller National Center. Her current loss of hearing and sight have not prevented her from leading an active life with plans for attending college when she graduates - either at Bowling Green University or Gallaudet University. As you will realize from reading the following poem, she also has skill as a poet who can put her feelings into words with poignant meaning.

You take one good look at me and say,
"Poor thing, she cannot see."
But because of all my strengths,
it does not bother me.
Though I may not be able to drive,
or to do tasks that require full vision,
I can still go on with daily life
and make my own decisions.
In my ears are two hearing aids,
one red and the other blue;
though my hearing is not as great as
yours,

I can still make it through.
To some, deafness is a horrible thing,
I am one who takes it well,
I don't need hearing to be happy,
to laugh, and to excel.
When I talk, my words unclear
I am hard to understand,
I do not need speech to communicate,
all I need is two things:
I am mighty good at typing,
I am learning ASL,
I do not mind using paper and pen,
or communication cards as well.
Diagnosed with CHARGE at birth,
I have had many operations,
but still I have accomplished much,
despite my complications.
So what I am saying to you, friends,
disabilities are not that bad,
they are what makes us special,
we are gifted and should be glad,

because each and every one of us,
is related in our own way,
we all have our mountains to climb,
not letting things get in our way.

NAT-CENT NEWS

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EDITORIAL
INTERNATIONAL SHARING

By Robert J. Smithdas, LHD, Litt.d, LHD

As readers will notice while reading this issue of NAT-CENT NEWS, there is a wide scope of information in these pages that points up the fact that we are living in a global community today where deaf-blind citizens are increasingly demonstrating their skills and talents to achieve success and independence.

The story of a family that has a set of triplets - three small sisters, deaf-blind from birth - is unique and fascinating. Their parents, a creative and patient couple, are rearing their daughters at home and helping them understand life's experiences.

In England, Graham Hicks has once again established a record. In his effort to raise funds to provide deaf-blind people with needed services, he has spent the past several years helping to call attention to their needs.

In other countries, new programs are being introduced to help deaf-blind groups attain higher education and greater social activities. Products and services are improving rapidly and there is a growing exchange of information, technology and services. At the Helen Keller National Center we have had visitors from Germany, Norway, Sweden, Russia and other nations who support growing programs in their countries that help to spread ideas on how to solve the problems of not being able to see and hear. All we need is a more consistent and readily available source of information that can be shared and expanded by deaf-blind men and women who want to increase their independence and be a real part of human society.

We've planted the seeds and will share the harvest in years to come.

DEAFBLIND LIONS CLUB CELEBRATES DECADE OF SUCCESS

By Cynthia L. Ingraham
Helen Keller National Center
(HKNC)
East Central Regional Representative

"The opportunity I bring you Lions is this: Will you not help me hasten the day when there will be no preventable blindness; no little deaf, blind child untaught; no blind man or woman unaided? I appeal to you Lions, you who have sight, your hearing, you who are strong and brave and kind. Will you not constitute yourselves Knights of the blind in this crusade against darkness?" – Helen Keller (June 1925)

On Saturday, November 13, 2004, the Pittsburgh DeafBlind Lions Club celebrated its 10th Anniversary of existence in grand fashion. Local surviving members (charter members) of the Club were in attendance as the world's first deaf-blind Lions Club convened to commemorate its 10 year anniversary.

The Club was an outgrowth of the Western Pennsylvania Association of the

Deafblind (WPADB), which was established as a fund raising, leadership and social network for deaf-blind consumers within the metropolitan area of Pittsburgh, Pennsylvania. Its first president, Richard McGann, agreed to dismantle the consumer group and form the DeafBlind Lions Club as a vehicle to create future community and national leaders within the community and to raise funds to support consumer attendance at the American Association of the Deaf-Blind (AADB) Conventions. McGann, a long time community leader who has Usher syndrome, was recognized for his forward thinking and dedication to establishing the Lions Club. In his acceptance speech he thanked and honored his late wife, Karen McGann, who was one of the charter members of the Pittsburgh DeafBlind Lions

Club. "Karen would be very proud of all we have accomplished and I know that her spirit is here today," McGann shared. "She believed so much in supporting deaf-blind people and I know that she would be happy to see that we are still working together after all these years."

Other notable recognitions at the celebration was a plaque for Lion Anthony Cicco whose contact and work with the HKNC regional representative spawned the inspiration for the Lions Club. Without the help of Mr. Cicco during the initial years, this celebration would not have taken place. His attendance at monthly meetings, providing guidance and unwavering support helped the Club endure throughout those rocky first years. Also recognized for excellence and dedication was District Governor Dr.

Dennis McCarthy, who was also an original charter member of the Club. "It is so wonderful to see all the growth that has taken place with this club over the years," McCarthy shared. "I never imagined that when I became a member of WPADB that I would one day be a district governor for the world's only deaf-blind Lions Club – this is awesome."

The Club has a long history of providing support to deaf-blind consumers, and has purchased a braille embosser for Pittsburgh Vision Services, made donations to a community outreach program for children, and hosts an annual event in the heart of downtown Pittsburgh on Helen Keller's birthday as part of HKNC's national Deaf-Blind Awareness Week. Students from the local Interpreter Training Program and Church Ministries frequently volunteer their skills during Club meetings and events. Many have gone on to pursue careers in the field of deaf-blindness, interpreting or rehabilitation services for people who are deaf-blind.

"So many people have been touched by this very special Club," said Jack Schimmel, past district governor. "As a person who's always had a hearing loss, I've learned so much from all my contacts with the Club members."

The past decade has brought great memories of growth for the Club and some sad memories of the members who were lost. Each deceased member was recognized in a special prayer by Richard McGann.

The Club is currently embarking on a fund raising campaign to send its members to the AADB Conference in Baltimore, Maryland, this year. Each year new members join and work very hard to keep the Club growing.

"Let's give thanks for these ten years of blessings and pray for more to come," offered McGann.

Richard McGann
gives special remarks

PITTSBURGH DEAFBLIND
LIONS CLUB
HOME CLUB

Cynthia Ingraham, Richard McGann, and interpreter/SSP, Laura Shipley

The achievements of this Club have been nothing short of amazing. Thanks to its efforts, deaf-blind children are receiving quality education, men and women who are deaf-blind have new friends and social opportunities, and awareness about the needs of people who are deaf-blind is spreading. On November 13, 2004, the community was witness to the fact that Helen Keller's charge to the Knights of the Blind nearly 80 years ago lives on in each member of the Pittsburgh DeafBlind Lions Club.

TRAINER'S GIFT TO CHANGE LIFE OF DEAF-BLIND YOUNG MAN

By Matthew Coleman

Reprinted from the newsroom of The Daily Leader, Brookhaven, Mississippi

March, 2005

For Robert Bell, independence comes in the form of a brown Doberman pinscher named Rocco. The 22-year-old deaf and blind McComb, Mississippi, resident was recently united with his service dog at a local restaurant. Bell used sign language to communicate with trainer, Beverly Greenwood, as family members talked about the dog and what it will mean for Bell.

Annie Gene Allen, Bell's mother, said

they recently moved out of an apartment to the home of her new husband, Roosevelt. She said the dog will help provide independence and companionship for her son. "He can go outside with the dog, go places and the dog will be his friend," Allen said.

Greenwood has been training Rocco at her residence for several months. In the coming months, Bell and Rocco will learn to work together. "For the next week, they won't do anything but be at home together," Greenwood said. Then, Greenwood said, there will be training sessions about every two weeks until both are adjusted to interacting with each other. She said the training pace will be up to Bell. "They'll learn continuously forever," Greenwood said. "I hope they're a pair for the next 12 to 13 years."

Greenwood has about 18 dogs working across the country, as far away as California. Rocco and Bell, though, represent the first time she has been able to train a dog for someone in her home area. "I'm just glad to see one working locally," Greenwood said. "I've always wanted to do a local dog."

Bell and Rocco were united following a request from Lu Coon, a nurse practitioner who works with Bell's mother at the Bogue Chitto Family Clinic. Coon said she learned about a service dog Greenwood trained for an autistic child and then made the request for Bell. "I've known him since he was little," Coon said.

Despite his disabilities, Coon indicated, Bell is able to function in society. "He does communicate. He is very intelligent," Coon said.

Jean Norton, Greenwood's partner in an equine rescue operation, said 2-year-old Rocco came from a Baton Rouge veterinarian who was looking for a good home for the dog. The service dogs Greenwood trains are mostly mutts and come from a variety of places, such as rescue leagues.

After getting a request for a service dog, Greenwood finds a dog, conducts a temperament test and, after passage, begins preliminary training. That training can take up to two years. Greenwood does not look for dogs unless she has a specific need. "I do not accept them unless I have a request for a service dog," Greenwood said.

She said there is no charge for the dog or her services. When necessary, she does try to get travel-related expenses covered through donations or other means. A service dog recipient must be legally disabled, Greenwood said. That can include physical or mental disabilities. A special account has been set up at a local bank for Bell. The account is to help with veterinarian bills, food and other dog-related expenses.

Greenwood is hoping for a long and beneficial relationship not only for Bell but for Rocco as well. "Service dogs have a wonderful life," Greenwood said.

WITH HONOR: HIGH SCHOOL GRAD, ROBERT MACKNIGHT, INSPIRES FAMILY, TEACHERS, FRIENDS

By Adam Klinker

Reprinted from the Ralston, Nebraska Recorder - Online Edition.

Tuesday May 24, 2005

His eyes alight with the anticipation of unveiling his latest source of wonderment - a static-electricity globe - Robert MacKnight gingerly lifts the apparatus out of its box and goes to work setting it up as his mother and father look on. This is what Robert does, his mother explains, as he searches for the plug, cord and adapter and makes the necessary connections to bring the purplish-blue waves of the globe's core to life. "He fixes things; puts things together. He loves to do this."

Robert raises one finger delicately to the globe and, perhaps feeling more than seeing the concentrated cord of electricity run to that spot on the surface, he lifts his eyes to his mother's and in his look is the base alloy of all genuine excitement.

"He loves electricity," says his mother, Calvert MacKnight, watching her son fixate on the globe and seeing his smile broaden even further. "This is his world," she adds. For Robert, it's a world that continues to broaden, even as he suffers the effects of Usher syndrome, a rare, inherited disorder that has robbed him of his hearing and is causing his eyesight to deteriorate.

While the world around him is silent and shrinking, Robert is nonetheless standing on the threshold of a vast, new promontory. Last Sunday, Robert graduated from Ralston High School (RHS) in a separate ceremony that attracted some 60 family members, teachers and administrators to celebrate the achievements of this young man who so many have claimed as an inspiration.

"There hasn't been a day since graduation that we haven't thought about it," Calvert said. "It's been a big deal for us. It's all he has known - these teachers and his peers have been so much a part of his life. They made it Rob's day."

John MacKnight, Robert's father, said though he has known his son has had a wealth of supporters throughout his life, the graduation ceremony crystallized just how much of a difference his son has made in the lives of those who have known him.

"Seeing just how many people came to the ceremony showed me what a great thing this district has done for him," John said. "They've put us in touch with so many people and given him a chance to touch so many lives and, really, Rob's made our lives richer by bringing those people to us."

From here, Robert ventures this summer to the Helen Keller National Center in Sands Point, NY, where he will spend three months receiving further training in life skills to become more independent, just another of the incredible steps Robert has taken.

Outside of his graduation, Robert has also held a part-time job at the Goodwill store in La Vista and, in spite of his blindness, he still manages to help out around the house as well. He pays particular attention to the MacKnight's landscaping, as well as the condition of the trees in the neighborhood.

"He always knows when its time to trim the trees around here," John said. "We'll take a walk around the block and he's so tall he knows when the branches are getting too close to his head."

Robert's attention to these details and his overriding compassion towards human beings as well, are just two of the traits he brought into Jackie Vehe's classroom at RHS every day. "He's an amazing person," said Vehe, a teacher of Robert's for nine years. "With all the challenges he's faced, all the adversity he's overcome, he always showed up to school eager to work and in a good mood."

Vehe said Robert reveled in being able to redesign the classroom's bulletin board with the changing of each season. A folder of his writing reveals his enthusiasm for each day and activity he took part in while at school and also notes the absence of classmates or teachers.

"When someone was ill, he would always ask about them," Vehe said. "He had to write them a letter and when they returned, he had to give them a big hug and welcome them back. He's just a very compassionate person that way."

In September 2003, after the fatal shooting of Omaha Police Officer Jason Pratt, Robert noticed flags in the area flying at half staff and asked for an explanation. "When we told him, he got very somber for a moment and he said, 'I have to write his wife a letter,'" Vehe said. "And so he sat down right then and there and wrote a letter to Stacy Pratt. And it's been like that for everyone in class who gets sick or loses a family member. He'll do cards and letters for all of them. He's a very compassionate young man."

Calvert said the stories of Robert's kindness and humanity could go on forever. "There's a story everyday," she said. "He's never stopped teaching us a little more about ourselves and how we can be better people. He bonds with everybody he meets."

As John said, Robert doesn't give a second thought to his own troubles. There's too much for him to do, he added. "He's worked hard to get to all of this," John said. "He just does better knowing that there are people he can help and work he can do, and he's never at a loss to keep on doing and doing."

The kind of persistence exemplified in Robert's work towards his high school diploma has marked his entire life, both

Vehe and his parents said. Deaf from birth, Robert quickly compensated for his disorder by learning sign language.

As he grew older and into the later years of elementary school, and his parents and teachers began to notice that Robert was developing another serious problem with the blindness that usually accompanies Usher syndrome. He mourned briefly, but picked himself right back up. "That was a sad day," Vehe said of the day it was revealed to Robert that he was losing his eyesight. "We were all just very sad to find out and Robert did go through a period of depression. We all asked what we could do and we tried to do everything that might work, but there was very little to do."

His funk didn't last long, though. Within days, Vehe said Robert had resigned himself to the fact of his blindness and immediately set out to learn braille and tactile signing, both of which he mastered in a matter of months.

Robert adapted to the new tasks of negotiating crowded hallways without seeing. He found ways to still enjoy the things he had loved since childhood, including nature and the changing of the seasons. What seemed to be an infinite store of compassion before his blindness set in grew even larger.

The commencement ceremony served as a testament to his character, his parents said. "People just kept coming up to him and to us and telling us how much they admired what he has done and what he will continue to do," Calvert said. "It's hard for us to realize just how many people have come into his life and how many people he's brought into our lives. All these people were here for our son and it was just incredible to see what they had to say about him. He's truly endless."

As Robert puts his globe back into its box, he knows something is missing. All the components are there: the globe, the stand, the cord and the adapter. But there's something else, too. He motions to the kitchen table and Calvert walks over and picks up a small booklet. "It's the instructions," she says, waving them in her hand. "He knew these were missing." She hands them to her son; he places them in the box and folds the flaps into their proper positions to close it up.

After he graduated, Robert came home asking his mother what he was going to do. Where he was going to live, how he was going to eat, whether he would continue working at Goodwill.

Preparing to depart for the Keller Center at the end of the month, Calvert knows her son is excited, but at the same time nervous about what life has in store for him. "It's a big step," she said. "And we'll know a lot more when he gets back."

Robert puts the box with his globe aside and makes a sign into his mother's hand. He seems to already have an answer of his own. "I'm going to a new school," he signs. "I'm going to learn new things."

EDITOR'S NOTE: Robert is now participating in the training program at HKNC and will continue here for several more months.

SHE USES HER HANDS AND HEART TO EMBRACE THE WORLD

Original Translation from Chinese to English by David Wong

Reprinted from News from Advocates for Deaf-Blind

A 22-year old young woman from Hawaii used her heart and smile to overcome her deafness and limited vision to make new friends. Cheryl Yee of Hawaii was born deaf and began to lose her vision at the age of 16 due to a rare, genetic condition called Usher syndrome. But despite this, she had the chance to make many new friends when she attended the World Leadership Camp in Taiwan in the summer of 2004.

The goal of the week long summer

camp, which was sponsored by the International Rotary Club, district chapter 3520, and Taipei Christian Youth Association (YMCA) was to cultivate leadership skills in youth who are deaf and blind. One hundred and twenty youth, representing 12 countries, participated in the camp. The goal of the conference entitled, "Use Both Hands to Embrace the World" was to cultivate and develop independence and youth leadership. The group also worked to promote international sign language. Currently, sign language is not universal, therefore limiting opportunities for deaf people from different countries to communicate.

Cheryl, who is Chinese American, does not consider herself handicapped. She communicates with American Sign Language and recently learned to read braille. Due to her limited vision, signers must stand close to Cheryl, use a small signing space and make sure that the color of their clothing is in contrast to the color of their skin so that Cheryl can easily see the signs. Yet despite these limitations, Cheryl was able to interact with participants from all over the world. She even became fluent in international sign language and hopes to teach her friends back in Hawaii.

The leaders of the youth camp hope that this forum will foster global cooperation and communication. Cheryl will surely be a wonderful ambassador for this effort.

MY LIFE AT HELEN KELLER NATIONAL CENTER

By Marcia McDermott,
from Indianapolis, Indiana

Marcia enjoys herself at an HKNC Holiday Party
Photo by Kelly Feeney

There is a special place for deaf-blind people. It is a very special community consisting of support, training, wonderful communication and great association, among many other things. This place is called Helen Keller National Center for Deaf-Blind Youth and Adults. It is located in the beautifully landscaped village of Sands Point in the town of Port Washington, Long Island, NY.

It was Helen Keller's dream to build this training facility for deaf-blind people to give them wonderful opportunities in life.

I spent almost two years of my life there. I arrived there April 6, 2002, and left January 3, 2004. In all my lifetime, I had never had so much support.

When I first arrived, I was not sure of my decision. I left my family and home to go to HKNC. But the mixed feeling was quickly evaporated and I came to love HKNC from the bottom of my heart (which somehow doesn't seem deep enough.)

I am very grateful to vocational rehabilitation for being so generous in taking the tab for my room and board and training there which is no small sum. My VR counselor at the time, Kathy Ashley, was extremely wonderful to me the 1 year and 9 months I was there. I received many wonderful assistance aids that are helping me make my life easier. I feel so blessed by EVERYTHING - vocational rehabilitation, Kathy Ashley, and many wonderful friends at HKNC.

The training there was very intensive. When a student left, the staff wanted to make sure they had everything they needed to get along much easier in the real world. Some of my training consisted of classes in independent living (IL) where you learn to cook, clean by using your sense of smell and touch, and do many domestic things that were hard to do before you went to HKNC or you were not aware of.

I learned to use special utensils in IL that made my domestic life so much easier. Some of the utensils that VR purchased for me, after evaluating what worked best for me safely, were a grip knife (this is a different kind of knife that helps me cut things better without the danger of cutting myself.) There is a HotShot beverage heater that makes it easy to make a cup of tea or soup without boiling hot water from a pan. There are prongs that help in opening and closing hot oven shelves; timers you wear around your neck; a device that lets you know when glasses or cups are full so as not to overflow; a skillet to use instead of the stove; and a George Foreman grill that is so easy to use and clean. These are just a few things among many.

Deaf-blind people often need assistance in the kitchen and with cleaning. HKNC trains students to do all this with a little help from special devices and utensils. It is wonderful to be able to cut things that I need to cut instead of waiting forever for someone to have the time to help me.

In IL we also learned how to cook many different recipes. I have a personalized book of recipes at home now. One thing I learned in IL which was very interesting is a quicker way to boil eggs in the microwave! You fill a microwave safe bowl full of water to cover the eggs, then you use foil to wrap around the eggs, then place them in the bowl of water, making sure the eggs are fully covered, then cook on high for 15 minutes. I always thought using foil in the microwave would make the whole system explode. But this system at HKNC REALLY does work. My love for egg salad sandwiches have proven this many times! It works in less time then doing it via stove top so I get my favorite sandwich much faster!

My instructor in IL was simply wonderful. She is deaf so I had the bonus of picking up signs from her. She is extremely skilled in working with deaf-blind people. We had a great relationship, learning together. Since we both had a sense of humor, it did wonders in dealing with everyday things. I will always be grateful to her and have a deep respect and love for her.

Although many students go there to learn to be completely independent, I had a different reason for being there. Most of my life I have been fiercely independent - sometimes to the point of overdoing it and injuring myself because of my serious balance problems. I needed to make changes in order to live more safely.

I had to learn to ask for help when needed and not be afraid to do this. It was a change that was hard at first. I always hated to ask people for assistance figuring they had much better things to do, so I always tried with all I had in me to do it myself.

Imagine the wonderful feeling of having others so willing to assist you and caring that you did not overdo it! I had to learn to listen to my body signals and slow down. That was the hardest thing to do - slow down - but I learned that it had a benefit for me and the result was I started to relax and not have so many tumbles in life. Again, I had quite a lot of support. As to those at HK - I knew they still respected me and had empathy and love even though I had to make some changes in my lifestyle.

HKNC has a job training program in which they match students with a job that might benefit them in the future. These jobs are voluntary jobs but HKNC pays the students every Friday for the work they did either inside the Center or out in the community. I had a job working for North Shore Animal League (NSAL). I dearly loved this job. It put me in contact with animals, which all my life I dearly loved.

I worked there once a week from 10 a.m. to 12 p.m. I had happy hours there taking care of the many animals. What I did was clean cages, making sure the animals had water, and socializing with the animals (which was the BEST part!) Sometimes I was tempted to "adopt" a baby kitten and take it back to HKNC but had to restrain myself in this situation.

My supervisor at NSAL was one of a kind. She was so understanding and a great advocate. I was the first deaf-blind student to volunteer at NSAL. That is such a wonderful feeling to open doors for other incoming students.

I also had a job at the HKNC Library. I went thru documents, writing down what they had in the library in order, and noting what might be missing or not returned yet. I also loved this job. But, due to my coordination problems which affect my hands, my pace was too slow for this kind of job. I really ENJOYED it and wanted to learn so much more and improve my skills in this area but time was running out. I hoped that when I came home to Indianapolis again, I could train for a job in the library. I have always had a great love for books.

Mobility training was a challenge since I broke my ankle about three weeks after arriving at HKNC and was in a cast for three months. Then I had to have more surgery so I was down again for awhile. But I sure learned how to get around in a wheelchair!

My mobility instructor was a wonderful, strong person - very sensitive and skilled at the mobility needs of her students. She taught me how to cross streets SAFELY. When she was asked by HKNC's representative in Indiana, Laura Thomas, at a case conference, about my mobility teacher's opinion of my mobility skills, she quickly replied "She has been independent since the day she arrived" (laugh). I just needed to learn to go at a slower pace and to look into getting a motorized wheelchair which I recently accessed. The problem is there are no ramps in my apartment building so I have not been able to practice using it much and that makes me miss HKNC's accessibility. It is so EASY to get around there!

I would have plenty of supportive practice, something I do not have here. But hopefully, in the not too far distant future, I will find an apartment or rented house that will make everything more accessible for me. That is one of my biggest dreams! Of course, HKNC helped me in developing this dream letting me know there is NO SHAME in needing "different" avenues of living. Before I went to HKNC, I thought I would be "stuck" in this apartment for life. HKNC changed that and I am working on moving to a different, more accessible place.

There is also a Creative Arts Department at HKNC. Students create and make many, many wonderful things. In Creative Arts, my talents lay in macramé, poetry, short stories, and creating my own greeting cards.

I got plenty of practice in these areas while at HKNC. One day soon I hope to work on one of my goals - a huge macramé wall hanging. I do make macramé ILY (I Love You) wall hangings. I was so grateful to get a refresher course in macramé at HKNC. It kept me busy and it was fun. I made several to sell. It was so nice to have the extra money by doing something creative. Many very beautiful things are made by those without sight and hearing. I loved watching them work.

One of my deaf-blind friends told me that Creative Arts was the place to go to if you became distressed, even if you can't make anything "beautiful." It is fun to pound on clay, make drawings in the clay or almost anything you want. The art instructor, Sarah, was a great person - very down to earth who saw people as people no matter how different they were.

Speaking of poetry and creating my own greeting cards, I attended a Stationary Show in New York City to give me ideas and contacts with people that do these things. This was so exciting! This past spring, one of my deaf-blind friends who uses graphic arts to make greeting cards, had his own booth at the Stationary Show and informed me that he made a lot of profit and many new customers.

In the CLC (Communication Learning Center), I learned to use sign language more. I also learned basic braille. My instructor and I worked on getting me into college classes at nearby Nassau Community College. In all the time I was in NY, I took three classes there. One class I needed to withdraw from due to needing foot surgery immediately. The other class was creative writing. I took graphic design, too. My college professor was wonderful. Since they used Mac computers there, he gave me a CD that had the same graphic program for Windows. I learned so much in that class and felt so successful in both classes, receiving A's in the two of them.

I am just very fortunate to meet with such wonderful, supportive people who truly understand my inner need to learn as much as I possibly can despite my disabilities which, at times, can cause obstacles for me. But with hard work and patience with myself and great advocates and interpreters, I learned to overcome many of these obstacles in NY.

In CLC, we also create communication cards. These are cards that make it quicker to state your needs. For example a communication card can say "Please show me where I can find these items ----" The cards are covered with special paper-plastic so that others can write on them. I also have a writing board that I use when there is a communication breakdown with hearing people.

Most often, thanks to my wonderful speech instructor, Alicia, people can understand me fine but most of the time, I do not understand the other people so this writing board has proven VERY handy especially in emergencies. I carry it with me all the time and it gives me some sense of security. Before HK, I did not know about these things so I really profited from this experience.

In speech therapy, I learned how to make my voice audible to other people and the exercises that help with this. I usually give people the impression of being as quiet as a "church mouse" and I learned not to be so self-conscious about my speech being a little slow - instead to assert myself and SPEAK UP! Alicia also taught me how to say some very troublesome words so my vocabulary has improved!

In the computer Adaptive Technology Department, I tested out many different adaptive tools to help me work better on my computer. I am now the proud owner of Zoom Xtra 7.0. This program magnifies the screen for me to the size that is most comfortable for my eyes. It also speaks, too, so when I feel like the apartment is too quiet for me, I just turn the volume up on the computer. My son states sometimes that my computer talks too much. (laughing)

I leaned the two key modes to use in case I didn't want or couldn't use the mouse. Vocational rehabilitation was so wonderful to purchase for me a brand new Dell Computer along with a HP Photosmart printer as I use a lot of pictures in making my own cards and I wanted things to look "perfect." Now I feel all set up to do all my computering to the best of my ability! I also worked some on Photoshop and Quartz. It is fun to learn graphic design! I learned how to do some programs in Windows such as Excel and Word.

It is always so stimulating and fun to learn new computer programs. Many students that go to HKNC get their first taste of how to use the computer and internet with assistive devices. Their horizons start to broaden. It is exciting to see this happen. I, too, depend on my computer. I would be lost without it. And that is an understatement.

A few months before I left, I moved to one of the ILE (Independent Living Experience) apartments. They have two different kinds of apartments. Some of them are off-campus, and the others are renovated rooms at the Residence to resemble an apartment. I lived in one on campus. I needed to get myself back in gear before returning to my life in Indianapolis. In this life, I do not have the everyday contact with people outside of my family, nor do I have much assistance in doing domestic chores. So this was important to me to get back in shape. The apartment is very accessible and easy to get around, cleaning, cooking, etc.

The apartments at HKNC are there for two reasons. 1) To help those deaf-blind youths and adults to learn to live independently when they have never touched on that base before. 2) To help those find different ways of doing things in independent living when they have lived very independently before their vision, hearing and in some cases physical coordination has decreased over the years.

I did much of the same things I always did when living on my own in this apartment at HKNC. My IL instructor taught me some tricks to make domestic duties a little easier. I was also taught to feel and smell rather than use my vision. I learned that you can tell if water is boiling by putting a wooden spoon in the pan with the hot water. If it is boiling, the upright spoon will move. This is safer then putting your face down into the steamy water to see if it is boiling or not. Of course, you might get a nice steam facial but sometimes we don't have time for that when we are cooking!

I lived in the ILE apartment for 3 months. I was given $500 a month to buy food and domestic supplies needed for the apartment. This money was taken out of the normal monies vocational rehabilitation gives for my room/board and training at HKNC.

The wonderful thing about HKNC is its one BIG family. You never feel alone here. And you never feel "different." At HKNC, sign language and tactual signing are like first language. Everyone signs. When you come from a world where communication is a problem - joking, laughing, and serious chats are almost non-existent when it is person to person, it is so wonderful to have an easy-going communication with others. It enables you not to focus on one thing and certainly broadens your horizon. For the first time in my life, I felt like a real person. It was a wonderful feeling to be included instead of being left out of good communication.

HKNC will always have a very deep place in my heart. You learn, you grow, others grow with you and there is always so much to share in life. Again, I am immensely grateful to Indiana Vocational Rehabilitation and my VR counselor, Kathy Ashley for enabling me to go to HKNC.

THE DEAF-BLIND CULTURE

A speech given by former HKNC student,
Marcia McDermott, Indianapolis, IN

As I sit here with my mind full of ideas of how to educate people in the area of deaf-blind culture, I keep thinking to myself, "We are people, too, very worthy of the same rights and opportunities as a hearing/sighted person, why are we not given these rights without so much overwhelming hassle and stress to surmount a MOUNTAIN?"

My answer is, because so many people use FEAR as an excuse. They do not want to identify with people who have disabilities - especially those who are deaf-blind. To me, this is a definite cop-out. And we, as people who are deaf-blind, suffer the consequences of other people's fears. We want to change that and educate you NOT to fear us.

Everyone in the world has some kind of disability. Most we cannot see, some we can. Everyone in the world needs help sometimes, too. No man is an island. But the way "normal" people react to people who are deaf-blind with other disabilities, it feels like an island all by ourselves.

My point is, it is a waste of time to discriminate and use fear as an excuse. There are so many deaf-blind people that are brilliant, have very special gifts and are more then just capable of taking care of themselves. But like always, sometimes we need some help in getting our full potential out in the open - contacts with others that can make our dreams come true - definitely, and with much vehemence, NOT to control people.

There are people that are trained to be SSP (support system providers). These people are awesome. They help with what the deaf-blind person wants, not what the SSP wants. There are wonderful rewards in being an SSP. You learn to really get to know the person who is deaf-blind, laugh and share and cry with them. And your fear starts to fly away bit by bit. Believe me, the deaf-blind person always gives back in little ways and big ways.

I've grown up deaf-blind with other disabilities since I was 18 months old. I am quite independent in most ways. All my life, I felt like an island to myself and I learned to be happy doing things alone rather then deal constantly with others' fear and pessimism. Some things in my life were very hard to do but I managed to get through many of the hard knocks in life without much support - except from my beloved vocational rehabilitation counselor, Kathy Ashley. I learned to be strong in facing the sometimes bizarre realities of life.

Then I went to Helen Keller National Center for almost two years. I never in my whole lifetime had so much support and unconditional love. I learned what a real SSP is. It was a wonderful revelation! I also want to share with you all that the deaf-blind culture is not the same as the deaf culture. There are things you do not do in the deaf-blind culture and close contact is necessary. Gentle touches to get a deaf-blind person's attention and to assure them gently. NOT waving your hand or papers in their face. Being a control freak is also a no-no. It causes the deaf-blind person to back away very quickly.

QUALITY communication is very important! Many people communicate with people who are deaf-blind as if their disability made a mark on them for others to communicate in a much less qualified way as if they were children and know nothing of the world and how to cope. Everyone needs good communication in order to grow and learn as you journey along life's road. Again, I cannot remind you enough times that gentle touches are very important - not just rushing into communication without a gentle touch on hand or shoulder - and then WAITING until they are ready unless it is an emergency. Very important.

RESPECT is also very important, too. Not constantly pushing their needs and wants way back on a back burner that other people always have an excuse for keeping it there without CONSTANT reminders.

ALWAYS, ALWAYS identify yourself to a deaf-blind person. Do not play guessing games when it comes to identification. For those who can see well enough to see the person and know them well, it is not necessary to identify yourself every time you meet. But it is different for deaf-blind people unless they know you VERY well - the feel of your hands have become familiar to them.

Deaf-blind people are worthy of respect, love, fulfilling dreams, desires and all the wonderful opportunities life has to offer.

I hope with all my heart this helps to make some of you more aware how beautiful and giving most deaf-blind people are. We all need people too, both deaf-blind and hearing/sighted, to help us reach our goals. Goals as simple as quality living, community involvement, meaningful and respectful relationships, and quality employment. We, as people who are deaf-blind, have put up a mighty struggle to be who we are and to grow and be a part of life rather then being pushed away by people that do not want to understand. It is time things CHANGED!!

As I end my presentation, let me add one of my own quotes: "Through every dark, lonely forest, there is always a bright light that guides us to the sunlight."

2004 OUTSTANDING REHABILITANT OF THE YEAR 2003 - 2004:

Lance Kamaka

From Hawaii Vocational Rehabilitation Services for the Blind's Newsletter

Lance Kamaka was born totally blind and has moderate-to-severe hearing loss as a result of Norries syndrome. He has spent many years developing his blind skills and attitude so he can live and work independently.

He now lives in his own apartment, is able to type documents, e-mail, network with special interest groups and do research for his work on the internet, using a screen reader called JAWS. He also takes notes and schedules appointments using a BrailleNote 32, creates and arranges music on a multi-track level, and reads braille at a proficient level. He has demonstrated his ability to do these things independently and at competitive rate.

As Lance's hearing loss worsened, his dreams of becoming a paid musician were put aside. He continued playing music at various nursing and senior citizen homes with his group, The Makalolos, on a volunteer basis. He developed his musical skills on his own and learned to play a sophisticated, 16 track keyboard from Michael Rozen, Sanders Piano salesperson, who provided years of training at no charge because, "I liked him and I knew he had talent."

Although Lance had more practical vocational goals in the past he did not find employment, and he felt his strengths and desires were in his music.

Lance changed his vocational goal to become a self-employed musician in 2001. He started to play piano two nights per week at La Mariana Restaurant in January 2002. Since then his days have increased to four nights per week, he has an original CD to promote his talents and playing engagements, and he networks with other musicians to play at other sites. Lance filed his General Excise, State, and Federal taxes for 2002 and 2003 for the first time!

EDITOR'S NOTE: Lance Kamaka is a former HKNC student.

DEAFBLIND TRIPLET DAUGHTERS NOW THAT'S A PARENTING CHALLENGE

By Jamie Berke, on the website of ABOUT.com

When I received an e-mail from Liz and George Hooker, parents of deaf-blind triplet daughters, I knew I just had to feature this family on the ABOUT website. As one of the parents put it: "As you know, deaf-blindness is a low incidence disability. I know of a set of seven year old blind triplets in California and a set of twenty year old deaf triplets in the Midwest, but I believe we have the only set of deaf-blind triplets."

At the time this article was written, their deaf-blind triplet daughters were close to turning five years old. Stated Liz Hooker: "We're lucky that the girls don't have any cognitive impairments beyond developmental delay. We work very hard every day to push them along. It is most overwhelming though, because I know I'm outnumbered to perform the task at hand. I still have big dreams for them though."

ABOUT: How old were they when you found out about the RP? Do they have any sight at all?

Liz and George: Emma, Sophie, and Zoe were born premature, at 25 weeks. Sophie weighed 1lb 3oz, Zoe weighed 1 lb 6 oz, and Emma weighed 1 lb 5 oz. All three became blind from complications related to retinopathy of prematurity. We didn't know they were blind until they were almost six months old. Sophie is legally blind, she sees colors and shapes, she also has tunnel vision. Zoe sees enough light to find the windows. Emma sees nothing.

ABOUT: How did they lose their hearing and how old were they?

Liz and George: They lost their hearing due to vancomyacin and gentamicin antibiotics that were administered to them throughout their time in the neonatal intensive care unit. The drugs were used to treat suspected sepsis. The two drugs when used together increase the ototoxicicity of each other. They were almost completely deaf when they were about 20 months old. It was a very difficult time for us because we didn't know what was wrong with them.

The girls had made significant progress their first year. They were about to start walking - they were saying cup and mama - then out of the blue they curled up on the floor in the fetal position. Everytime we drove them in the car they would throw up, our happy babies became angry and began to bang their heads on the floor. We took them to the doctor thinking that their stomachs hurt; we had no idea they were losing their hearing.

The reason they were curled up on the floor is because ototoxic drugs damage the hair cells on the cochlea which in turn causes deafness, in addition they also destroy the vestibular hairs. Due to the vestibular damage, the girls were experiencing severe vertigo and could no longer hold their heads up. They also became mistrustful during this time. They all got real clingy and wouldn't roughhouse anymore. They would get scared when you picked them up off the floor, they always seemed to be on edge.

It has taken three more years for them to recover and begin walking again. Most of the angry behavior is gone too. But the deafness was a huge setback for us. We hate to think of that time because we wonder if they thought we had just quit talking to them.

When the triplets were two years old, they received cochlear implants.

ABOUT: How much benefit are the girls getting from the implants at this time?

Liz and George: Sophie is at a 22 month old level of language while Zoe and Emma are about 10 months in language development. They all have the Nucleus 24 cochlear implant. They hear most speech sounds. The reason Sophie is so much more advanced is that she is legally blind. Your vision helps give meaning to sound. For example, if you hear a squeaking sound and then see a swinging door then you can associate the two. Say someone is talking while the door is squeaking, you can then determine that the door is unimportant and tune it out, and listen more to the person talking.

In a room right now one might hear the ceiling fan, air conditioning vent, dryer, radio, cars outside, and still carry on a conversation. Through normal childhood development you learn to filter sounds and determine which sounds are important at different times.

The challenge with Zoe and Emma is that they see through their fingers. So we must talk about whatever they are touching to help make sense of their world. To help them tune out the background noise we have to take them to the air conditioning vent and let them hear the noise as they feel the air coming from it, let them touch the dryer as it tumbles the clothes. These are all great exercises to help them distinguish sound.

What makes it more difficult is when Zoe and Emma are touching different things. If we say "Zoe, your eggs are lumpy and hot," while Emma is eating ice cream, then Emma may associate lumpy and hot with ice cream. You can see how it gets more difficult from here.

In summary, the expectation is that all the girls have the tools to talk - we just have to help them sort out their world first.

ABOUT: What educational approach is being used?

Liz and George: They are being educated with an oral and sign approach. We sign and say everything within their routine. We hope to mainstream them in the future but we believe the girls will always have some sort of interpreter in school.

ABOUT: How do they play with other

children?

Liz and George:They don't really play with other children. Very rarely do they play with each other. Sophie will laugh and become excited when she sees her sisters trying something new, but that's about it. They eat off each other's plate, steal one another's cups and pillows - they are definitely aware of one another but that's about it.

ABOUT: What is life like with deafblind triplets?

Liz and George: 24 hours of hard work. Blind kids don't sleep well, so we rarely get a full night's sleep.

We are working on table manners but spills are frequent so we are constantly sweeping and mopping. Two of our triplets are not potty trained so we go through quite a lot of diapers. We're constantly on watch to make sure they don't fall down the stairs, or run into something. They can't tell me if something hurts, how they're feeling, or if they need a cuddle. In those ways, it's a lot like having infants. We worry a lot about meeting all of their needs. It's quite a bit of guesswork.

There's good parts too. Those first steps were like watching them win the marathon. They work so hard for every little gain. The highs are higher and the lows are bottomless.

Having deaf-blind triplets is going to bed every night knowing that we didn't do enough. The odds are stacked against us. There is no way for us to give them everything they need. Sometimes we wish that if it was our fate to have three deaf-blind children that we could have them five years apart just so we could give each of them all they need in these developmental years. We're not quitters though and we are making slow but steady progress. We just pray that God will fill in the gaps where we couldn't.

ABOUT: What is a typical day with your triplets like?

Liz and George: We wake up about 7 a.m. and test their cochlear implants and put their batteries in their packs. Then we wake the girls by rubbing their backs. We help dress them and change their diapers. We walk them into the bathroom and help them brush their teeth and then fix their hair. We walk them downstairs one by one and put them at the kitchen table where they get breakfast.

After breakfast, we give them their canes and walk them out the bus stop. They go to school Monday through Friday for most of the day. The girls are in their own classroom and they have one teacher and two paraprofessionals. They take the girls through a routine that concentrates on routine.

In the afternoon at home we have private therapists (OT, PT, ST) four days out of the week. We try to take them outside if the weather is nice. The younger kids in the neighborhood will often stop by and say hello. We try to have the house cleared out by 7 p.m. so we can eat like a family.

We eat dinner hand over hand with the girls. They are pretty good at picking up the utensils they just tend to throw them down after taking a bite. Sophie will eat anything that you let her dip into ketchup. We take our time eating dinner. About 8:30 p.m. they take a bath together. They LOVE their bath, which is a good thing because they really need it after supper. We put them in their jammies and to bed about 9 p.m. Emma usually stays up until midnight and then Zoe wakes up until about 3:30 a.m.

On weekends we will spend a lot of time outside. We have a small trampoline, and rocking horse. We'll get some Playdoh out or some other toys. We then rotate their activities every hour like a circuit course.

ABOUT: Does Sarah help? In what way?

Liz and George: We call Sarah the invisible child. She stays away from the commotion most of the time. We encourage her to play with her sisters. When we take all of the kids somewhere she helps guide one of them. She fetches diapers, cups, and little things they need. She helps me watch them at the park. She likes to fix their hair too.

ABOUT: Is it any easier to raise deaf-blind children today compared to Helen Keller's time? Compared to a decade ago?

Liz and George: The technology of hearing aids and cochlear implants definitely gives deaf-blind children more access to their environment. We also have school systems that legally have to put together some sort of education plan for disabled children, so they are guaranteed an education. But we don't have an Annie Sullivan, someone willing to devote their entire life to a deaf-blind person. We don't know that we'll find three special people like Ms. Sullivan in this day and age. Helen Keller's life proved that deaf-blind people can learn and contribute to society. That's made a huge difference in how the girls are educated. We think Helen Keller's success raised the bar. And that's a good thing.

HIGH-TECH HOME HELPS DISABLED FAMILY

By Kara G. Morrison

Reprinted from The Detroit News

November 2004

"Overwhelming" is the word the Vardon family keeps using over and over to describe the transformation of their lives. The parents, Larry and Judy Vardon, who are deaf, had trouble communicating with their 12-year old blind and autistic son, Lance. Their 15-year old son, Stefan, was literally the family's eyes and ears. And Larry Vardon worried that his salary as a welder wasn't enough to provide all the best things for his family's special needs.

But now, thanks to ABC's "Extreme Makeover: Home Edition," the family lives in a home that is a miracle of modern technology that gives them a sense of peace, safety and security that they never thought would be possible.

In November 2004, the country got to watch, and even choke back a few tears, as they saw the Vardon home rebuilt from floor to ceiling in a special two-hour episode of the hit ABC show, which each week makes over the houses of deserving families.

In August 2004, because of an appealing letter from Stefan, a TV crew arrived at the Vardon's door. In a seven-day whirlwind of activity, construction crews totally revamped the family's small ranch house.

"I never thought that it was me on TV," Judy Vardon signs from her new living room while her son, Stefan, interprets her sign language. "It's unbelievable."

It wasn't the new sauna, Judy's arts and crafts room, Larry's new tool shed or even the marble countertops in the brand-new kitchen that blew away this amazing family. All those perks have been terrific. But Larry Vardon says the show gave them something more valuable: peace of mind and a better way to communicate with one another.

Larry says he's able to relax a little more and not worry so much about Lance's safety now that censors on the doors will tell him whether Lance has gone outside. The family had awakened more than once to see Lance's room empty, only to find their son wandering the neighborhood at night. Now, if Lance leaves the house at night, the parents' bed will vibrate to wake them up, and a white light will flash in their room. A system of locked doors with combination keypads also keeps Lance from entering rooms that are off-limits.

A new braille machine also helps Lance type notes to his family that are translated on a computer. They can then type an answer that's embossed in braille. Lance's favorite additions are a huge new swingset in the back yard and a high-tech playroom built just for him in the basement.

While most of us take for granted being able to talk to our loved ones in another room, the Vardons must see one another to communicate through sign language. Today, they can communicate from anywhere in the house with the aid of security cameras and computer screens in each room, in addition to a better floor plan.

"Everything is open," Judy says,

explaining how some of the walls were taken down so she can see both the living room and dining room table from her kitchen. "We can communicate easier. We talk more."

As for finances, the monetary perks also lifted a burden. Fairway Construction Company spent more than $200,000 on the renovations while Art Van supplied more than $10,000 in furniture. Stefan even was awarded a $50,000 college scholarship from the Starkey Hearing Foundation in Minnesota.

The family is taking their newfound fame and the media coverage in stride. On Stefan's birthday, Bob Woodruff of ABC's "Good Morning America" and camera crews arrived. However, Stefan said, he'd already gotten the ultimate present. "It was pretty neat," says Stefan. "It was really overwhelming to see everything happen."

They are getting used to the occasional car driving slowly through the neighborhood, peering at the house. And, they've been savvy enough to rent a post office box for those who wish to write cards and letters.

Adam Becker, vice president of Fairway Construction says that the Vardons are "a family that has more love in it than most of us ever realize in a lifetime. It was truly meant to give back to them and make them able to have things that we have every day."

At the dramatic moment when the house was revealed to the Vardons in August, more than 6,000 people showed up to watch the couple erupt with joy. Instead of cheering loudly, the thousands who gathered waved their hands silently in the air - the sign language for applause - as a tribute to the Vardon parents and so the event wouldn't be unnerving to Lance.

In addition to the vibrating bed, the flashing lights, the touch keypads, the security cameras and computer monitors and the braille translator (BrailleNote) other high-tech changes made in the Vardon's home include:

A Global Positioning System device attached to Lance's clothing or pajamas which shows the family where he is at all times; and cell phones for the whole family that ring or vibrate and let them email one another.

Judy Vardon, who volunteers with blind and deaf children, says her family is enjoying her beautiful new kitchen and all of the new high-tech changes to their home. Ultimately, though, she says while their lives have gotten a little easier, their good fortune hasn't fundamentally changed them. "We feel our family is the same, because our love is the same," she says.

CERAMICS AND OTHER HOBBIES AN AUTOBIOGRAPHIC ARTICLE

By Christopher Cook

(Editor's Note: Christopher Cook was a student at the Helen Keller National Center several years ago.)

Writer's note: I have written articles about myself and my hobbies for the BRAILLE Mirror magazine. I have also submitted some for other magazines. Now in this article I mention all my hobbies in general.

I started working with clay when I was 13 years old at Elmer O. Green Junior High School in Oxnard, California, where I grew up. During that time I made a few dinosaurs, a man's head with a hat on, and a couple of dishes. Then when the semester was over I had to give up that class and go into science. However, I renewed working with clay when I was 16 at the California School for the Blind (CSB) in Fremont, CA. I made more dinosaurs, and then moved on to other animals, and also began making people figures.

I've learned from past experience in working with clay that a very skilled artist must beware of certain things, such as air bubbles, wetness and thickness. All those things can cause an explosion. Air bubbles are the worst thing, because they can cause an explosion violent enough for one individual project to destroy other projects nearby.

Also, in glazing, I must take care not to get glaze on the bottom surface of the piece, or let pieces touch each other when loading the kiln.

I've worked with clay at different places besides CSB, including Contra Costa College, Humboldt State University, Ventura College, Gallaudet University, the Lighthouse for the Blind in San Francisco, The Braille Institute in Los Angeles, where I currently live, Los Angeles City College, the Santa Barbara Braille Institute, and even at home in Oxnard, where I used to live. Altogether I've worked with clay for twenty-four years.

I've worked with different kinds of clay.

I've worked with sculptey clay, oven bake clay, and air dry clay. Sculptey clay is rather like a plastic clay. You bake it in the oven for about 20 minutes at 275 degrees. You don't need water for it. Oven bake clay is like kiln clay, as you do need water for that, but you bake it in the oven for a whole hour at 350 degrees. Air dry clay, you just let dry.

I use acrylic paints of all different colors on the pieces after making them, and then cover them with clear varnish sealer, sometimes clear matt, which doesn't shine. I use the former on land animals and the latter on water animals.

Sometimes I make characters out of clay from cartoons and storybooks. I made super heros like Batman and Robin, Superman, Wonderwoman, Spiderman and Captain Marvel. I never tried making the

Incredible Hulk because I'm not familiar with his appearance. I've also made other characters like Snoopy in the Peanuts cartoons, Godzilla the gargantuan lizard from Japan, and Speed Buggy the talking car. I made book and movie characters like Frankenstein, Dracula, the Mummy and the Wolfman, and once I even made the Headless Horseman in "The Legend of Sleepy Hollow." In order to make them I had to use my memory of what I saw in the past.

I wasn't always deaf and blind. I had some sight, but it was less than normal. I could only see with one eye, and could never read print, so had to learn braille from kindergarten up. It was at age 14 that my sight began to fail me. Before that happened I had to have my right eye completely removed because it was in bad shape. Then my hearing began to fail me when I was 13, and the older I got the worse it grew.

If you wonder what causes these handicaps it was something called Voight-Carnegie syndrome, which is very rare and not heard of by many people. In the past, I sometimes felt very grieved and depressed about losing my hearing but I have my cochlear implant now and am proud of it.

I sold many things I made out of clay at Ventura College to make enough money to buy a Toshiba laptop computer and a thing to go with it called a screen power braille. Ed Elrod, the former manager of the Ventura Century Bookstore which is now out of business, and a bunch of other people helped me get that machine. They set up an art walk at his store where I was in a window demonstrating my talent with clay. Some interpreters who had worked with me at the college stopped to chat with me and some other people bought things while I was there.

I had the Toshiba for several years, and enjoyed using it, but gave it up about three years ago and now have a new computer called a BrailleNote. I got it with help from the Pasadena Department of Rehabilitation. I like it better than my old computer. Besides e-mail messages, I can also use it for telling time and dates. Another thing I like about the BrailleNote is that it takes up less space on my desk, and is very portable. It also has a book reader program.

I think I should share some funny experiences I had with certain things I made out of clay in the past. I think you'll be amused!

Once I made a green two-headed dragon out of kiln clay at Humboldt State University, where my oldest sister used to be, and a lady teacher bought it. Then I made a blue three-headed one. I gave this one to my sister's friend, a young lady from Malasia who was Chinese. It was a Christmas gift and I also gave her a model of a panda bear. She really liked the dragon. This fellow with a learning disability who worked at the ceramics class as an aid, said it would have cost a lot of money to keep a three-headed beast as a pet. You would have to buy food for all three mouths, although it only had one stomach.

Once while I was still living in Oxnard I made a variety of little dogs out of clay. I made every kind of dog I remembered seeing. Then when I was satisfied with the variety of dogs, I stopped making them and started making a variety of pigs. I made pigs of all different colors, included one gray wild boar with tusks. So it seemed that I took a change from dogging to hogging.

Once at the Living Skills Center in San Pablo, Patty Williams, the current director working there, was interested in buying a red kangaroo with two babies in its pouch. So I sold it to her. She said it was like her in a way. It was a mother with two kids and she was that herself.

Kathleen Anderson, a teacher at the Living Skills Center, asked me to make her a porcupine for her husband for Christmas. Porcupines are the hardest things to make because of their quills. I usually make them in a sitting position so that their quills lie down, and on a pad of clay so that they can be moved around without breaking off the quills. Kathleen said her husband was sometimes called porcupine as a nickname because he was bristly.

Once while at the Living Skills Center, Denise Vancil asked me to make her a snail that she wanted to buy for a friend of hers who was French. French people have been known to eat snails. She told me that when she gave it to him, she said he could have it but he couldn't eat it.

I collect many animal models, shells and coins. I have animal models from all the continents and have them categorized according to where they are found. They are made of clay, wood, metal, stone, glass, rubber, plastic, and some are stuffed. I make natural scenery to go with the animals like lots of trees and bushes. I make fields of grass out of green paper and water out of blue paper with Saranwrap over it. I have made snow for the polar animals and caves for dragons and dinosaurs.

Most of the coins I have collected are kept in a large plastic showcase. I have coins with pictures of various U.S. presidents as well as coins from England, Spain, Greece, Germany, Canada and elsewhere. Whether they are worth anything or not, I find them fun to collect.

I do take pride in my hobbies and I think it's wonderful to be an artist, a collector and a computer user. I hope to continue my career as an artist as long as possible.

DEAF-BLIND MAN BREAKS WORLD RECORD TO DRIVE HOVERCRAFT ACROSS SOLENT

Reprinted from Hov Pod HoverCraft Home Page, England May 2005

Graham Hicks about to achieve another "first."

Blind since the age of six and deaf since three, Graham "G-Force" Hicks, an ambassador for the charity Deafblind UK, achieved a world record first. On May 2, 2005, he flew a Hov Pod 3-man hovercraft across the Solent and back, a stretch of water separating the Isle of Wight from the mainland of England.

The Hov Pod is so easy to fly, that Graham learned how just the day before under the supervision of Hov Pod dealer

Alex Emson of Hover the Wight.

Graham Hicks can neither see nor hear. To enable Graham to drive the Hov Pod to complete the task, Alex communicated to Graham through touch communication hand signals. Alex assisted Graham using only touch to guide him out over the beach before flying out through the surf into the sea.

Starting from Ryde, a seaside town on the Isle of Wight, Graham flew with Alex, plus Graham's assistant, Robert Hall, across the Solent to the UK mainland at Southsea. Graham landed close to the HoverTravel Terminal at Southsea from where the regular passenger hovercraft service operates using a AP1-88/100, capable of carrying 80 passengers. The crossing took just 18 minutes! Graham then flew Alex and Robert back across the

Solent to the starting point in Ryde.

Graham smashed his way into the record books in 2004 by setting a new Guinness quad-bike world speed record of 133 mph supported on that occasion by his pillion rider, Cambridgeshire policeman, Brian Sharman. Graham's achievements also include the fastest journey from England to Holland and back on a Jet Ski.

Graham undertakes these amazing challenges to illustrate that a disability, even one as severe as deafblindness, is no barrier to achievement when given the right support. Graham also heads up the challenges department for national charity Deafblind UK, where he works to raise both the profile of the charity and vital funds.

In the UK today an estimated 24,000 people are deaf-blind or dual sensory impaired. This means they have sight and hearing loss to such a degree that it leads to problems with communication, mobility and accessing information.

Deafblind UK is a national charity that provides a range of support services to deafblind adults and their caretakers. It also campaigns on behalf of deafblind people. For further information please visit www.deafblind.org.uk/

NAT-CENT NEWS

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EDITORIAL:
USE YOUR IMAGINATION

By Robert J. Smithdas, LHD, Litt.d, LHD

For the past two years, I have been reading reviews of new technologies that are changing the lives of blind and deaf-blind people, not to mention other disabled groups that are also developing new ways to combat the limitations of being disabled. It is mind boggling to realize that science and technology can, in just a few short years, change problems that used to seem insurmountable and make this world so much more accessible.

Back in the seventies, computers were the major new source for information, communication and personal expression. But it wasn't long before busy inventors added a flood of creative software that opened new avenues of genius. Today we have computers that provide the means for making spreadsheets, using graphics, enhancing photography and home movies, and building models for scientists to use in forecasting weather and exploring natural phenomena previously beyond reach. And the impetus has not slowed down - in fact, it seems to be moving ahead more creatively.

More recently in the fields of blindness and deafness, there has been remarkable progress in devising new techniques to minimize the effects of not using hearing and sight as sources of direct information. One only has to think of the rapid growth of cochlear implants that enable deaf individuals to hear and recognize sounds and speech and the continuing progress in developing electronics which has already proven that a few individuals can now see light, movement and color.

In this issue of NAT-CENT NEWS you will read about a few new developments that are already coming into the market. I have inspected braille displays that are very light and portable and can easily be carried from place to place. Now the MPO's are coming into use - devices that are light, portable and can be used with cell phones for communication with braille displays.

Obviously one of the real gifts that human beings have is imagination - the ability to dream about what seems to be presently impossible and make it practical and useable in daily living. We are on the edge of a new creative future that could open up many secrets of our world and make life richer with information. All we need now is a genius who can solve the most difficult problems by using his imagination when he finds a special need.

STUDENT INTERNS GAIN VALUABLE WORK EXPERIENCE

From Eyes on Luxottica

October, 2005

For the past six months, a number of industrious young individuals from the Helen Keller National Center (HKNC) have been working here at Luxottica in our Returns and Shipping Departments.

Notes Kathy Mezack, coordinator of vocational services for HKNC, "This is a true win-win situation. We are grateful to Luxottica for providing this valuable hands-on vocational training to our student interns, plus in return, we feel Luxottica is reaping the benefits of having outstanding assistance."

At the HKNC headquarters in Port Washington, students also prepare many of Luxottica's mailings. The envelopes are stuffed and labeled and ready to go.

Shiela Wienclawski works on a mailing for Luxottica.

Says Annette Trewick, Luxottica's manager of the lower level warehouse, "We are grateful to these first-rate interns for their valuable help and assistance. They are a pleasure to work with and to know."

DEAF, BLIND AND A COOK!

By Jennifer Parks

Reprinted from the Edmonton Sun,
Edmonton, Alberta, Canada,
June 24, 2005

Rita Turgeon sits in front of her braille writer, typing out a recipe for coconut-cream cheesecake. After finishing a line, she pauses and runs her fingertips gingerly over the row of dots punched into the paper. Her stomach growls, and she chuckles. Typing the recipe is making her hungry.

Turgeon, 46, turns to her right toward her intervener, 25-year-old Marie Mulvihill. The deaf-blind woman reaches her hands out into the darkness and Mulvihill, who acts as her disembodied eyes and ears, takes them into hers. Using tactile sign language - hand signals Turgeon reads with her fingers - Mulvihill gives her the next line of the recipe to type. "Mmmmm," says Mulvihill, rubbing her stomach, with Turgeon's hands still in hers. Both women are craving the sweet dessert now. They laugh. "I'll give you a slice when I make it," Turgeon promises, signing back with a smile before returning to her work.

She loves to bake, and the braille recipe cards let her be self-sufficient in the kitchen. That's why she's so meticulous with typing them. Turgeon is a modern-day Helen Keller.

Mulvihill is an employee of the Canadian National Institute for the Blind (CNIB) in Edmonton. She's what Helen Keller's teacher, Anne Sullivan, was to the deaf-blind girl: a facilitator who taught her client to navigate through her silent, black world and live independently, despite her disability.

The women have spent many an afternoon together, translating recipes, taking walks, running errands - like grocery shopping and banking - and attending craft classes at the CNIB, where Turgeon has a chance to socialize with other deaf-blind people.

"I feel very independent at home and when I'm out in the community with my intervener," says Turgeon, who communicates by signing to Mulvihill, who then interprets for others in the room.

Every June, the National Helen Keller Deaf-Blind Awareness Week is celebrated. This year marks the 125th anniversary of Helen Keller's birth. "We want to promote awareness of this disability and celebrate a woman who played a major role in raising the profile of deaf-blindness around the world," says Mike Pawly, co-ordinator for deaf-blind services at CNIB in Edmonton. Part of raising awareness, he adds, is sharing the stories of people like Turgeon, who are deaf-blind, but thanks to their interveners, don't have to live in the silent darkness.

Turgeon has Usher syndrome, which is genetic. She was born deaf and gradually went blind in her late 20s. "It was a slow process," signs Turgeon. "It was also scary." She relates how she had to start staying home at night because she was afraid of getting hit by cars and couldn't catch a bus anymore because she wasn't able to make out the bus numbers fast enough.

Her sister, Celine, 42, who lives with her, is also deaf and has lost her night vision. One day, she, too, will be completely blind. They have an eight-year-old cat, named Snowy, who is deaf, but ironically still meows for attention at full pitch. Turgeon can sometimes make out the cat's shadow and, for fun, tries to sneak up on him. But she needs to do more than shadow-read to get by in the world.

Turgeon requires an intervener to do the things seeing and hearing people take for granted like going to the local Safeway to buy a carton of eggs. Mulvihill serves not only as a driver and a walking guide, she relays information about what's happening around them. This can include everything from how crowded the store is and the price of products to what's being said to Turgeon at the checkout counter so teller and shopper can carry on a conversation with Mulvihill acting as an interpreter.

The goal is to provide Turgeon with a full picture of what's going on so Turgeon can make her own decisions about things and be as independent as everyone else. The intervener does not offer her opinions, just her eyes, ears and undivided attention to keep Turgeon connected to the world.

Every client's needs are different, says Mulvihill. "Some want to know everything that's going on: if there's traffic, what people look like, how many shoppers are ahead of them in line. They say 'tell me more' or 'I don't care,' so you get to know the kind of information they want as you get to know each of them," says Mulvihill, who trained at the CNIB in Toronto after studying to be an interpreter at Cambrian College in Sudbury, Ontario.

"Rita likes to know what's going on but doesn't care about the details." Unless, of course, it's a recipe for coconut-cream cheesecake - then she's a stickler.

DESPITE SETBACKS, THEY DIVE INTO LIFE

By Lauren Peterson

Reprinted from the Los Angeles Times, May, 2005

Pasadena Westridge's school colors are green and white, but those hues don't mean much to senior swimmer, Eliza Cooper. "I used to sort of remember colors, but I really don't anymore," she said.

Huntington Beach Marina senior swimmer, Drew Hunthausen, once readily deciphered balls and strikes as a talented Little League player. Now, he couldn't recognize either if the pitch whizzed by him.

Cooper and Hunthausen are the lone blind students at their schools, and both responded eagerly when others floated the idea of swimming as a plausible athletic endeavor. "I wish I could still play baseball and golf too," Hunthausen said. "That's something I miss. But this is kind of like a trade-off."

Hunthausen, 17, was a healthy 11 year old when he contracted bacterial meningitis in 1998. In a coma for nearly five months, he came out of it blind, deaf in his left ear and with partial hearing in his right. He also was troubled by balance and muscle problems. "It was a life-changing event for all of us," said Hunthausen's mother, Jan. "His cognitive skills are fine which is the miracle of it all. Now it's a matter of overcoming all the physical problems."

Cooper, 18, has been blind since the age of 3-1/2 as a result of glaucoma and cataracts and a variety of congenital eye problems. A varsity backstroke and spring-freestyle specialist, she placed 13th in the 100 yard Prep League preliminaries. "Swimming just sort of became a challenge," she said. "I thought it would be fun if I could do it and I did prove that to myself."

She dove off the starting block in

competition for the first time during league preliminary races, and started races in the water during the last two seasons. "It wasn't the best dive. We hadn't done it much, so I was just hoping that I didn't crash and I didn't" said Cooper, who also executed flip-turns for the first time in the meet.

Cooper is guided around the pool deck by a teammate or other student. "I do it all the time," said Noelle Kenny, a sophomore breaststroker. "You really feel close because you're always right next to each other."

Cooper uses a hand-held computerized braille note-taker and has maintained a B average. She also sings in two campus choirs and is a member of the Los Angeles Children's Choir. She will attend Connecticut College, a private liberal-arts school in New London. Like Cooper, Hunthausen is a good student with a 3.5 grade-point average. But his hearing loss and lingering physical problems, as well as Marina's large campus with ongoing construction and an enrollment of more than 2,600 students, make many parts of school life more difficult.

Hunthausen is guided by one of several school-funded aides and another aide helps take notes in his classes. Classwork is converted to braille on a voice-activated home computer each night, and the assignments are translated to the standard written word by a specialized printer. This process can be laborious and often keeps Hunthausen up late. "It's not the easiest thing. Some classes I have to work pretty hard and it's frustrating. To keep a good attitude is the only way I can keep going."

Swimming helps. "I wanted to be involved with something to keep me busy and just to be around more people," Hunthausen said. "At meets, it's great because I can sit with the team and be in the loop."

He can't swim as fast as other members of the junior varsity team but is content to race the clock and happy that his time in the 50-yard freestyle has improved over the year. Hunthausen turned to swimming largely for social interaction, but his array of problems make it hard for him to start and maintain friendships. "Kids could walk by him every day and they might be saying hi to him and he might not know it," said Drew's father, Tony.

Hunthausen, who also snow skis with the help of a guide, appears to have the unconditional admiration and support of teammates and opponents who readily cheer him on as he races. But one-to-one personal interactions prove difficult, if they go on at all. At practice, Hunthausen spends nearly all his time only in the company of his aide. "It's not that we avoid him," said Ashley Fisher, a junior sprinter on the team. "I hug him after races and say 'Hey, Drew, good job' But then I'm not really sure what to do."

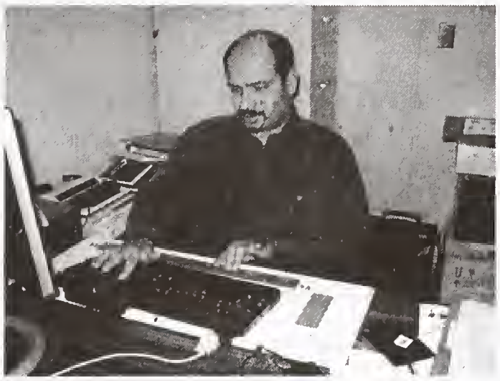
Hunthausen is open about his difficulties. "I don't have specific memories of before I was sick," he said, "but I definitely know I've come a long way from when I first came out of the coma."

FLYING BLIND AND DEAF BUT NOT ALONE

By Anindya Bhattacharyya

Reprinted from the NY Times

August 30, 2005



When you are deaf-blind, technology is an ever-present companion. I travel with a laptop for e-mail, phone and Internet access. I use a GPS equipped BrailleNote note-taker to get information about my surroundings. To communicate with others, I have a Screen Braille Communicator with two sides: one in braille, which I can read; the other an LCD screen with a keyboard, for someone who is sighted. My other traveling companion is my guide dog, a yellow female Labrador retriever named Dinah.

But there is no substitute for the human touch. For example, printing letters on my palm is sometimes quicker and easier than the Screen Braille Communicator. And I still have to rely on other people everyone from flight attendants, hotel clerks and cab drivers to the airline staff escort I need to get through security. Occasionally, I also turn to other travelers for assistance.

One of my most memorable experiences with a good samaritan happened a few years ago. My flight from Atlanta to New York had been canceled. The next flight was supposed to leave at 9 p.m., but by 8:45 p.m., we still hadn't boarded. Someone finally came over to tell me the flight was now scheduled for 11 p.m. and that it would be a different flight, going to John F. Kennedy Airport instead of La Guardia. But 11 p.m. came and went, and I still didn't know what was going on.

I started waving my arms to attract someone's attention, and a man came over. I showed him my communication card and how to print on my palm. His name was Allen and he told me we were delayed until midnight. He said he would sit with me on the plane. We finally boarded, and when we sat down, I realized we were in first class because the seats were leathery and the armrests were wider.

I was so exhausted that I napped often during the flight. Allen became my interpreter, making sure I got any food or drink I wanted from the flight attendant.

I figured they must have upgraded us because of the delay. I sometimes get bumped up if there are open seats because airlines often don't have much room for Dinah. I always try to get the bulkhead seat, but there have been times when my canine companion ends up sitting in the aisle.

When we landed, Allen helped me find my bag and a cab to the Helen Keller National Center. I asked him how much it would cost me to get back to the office, and he traced on my palm with his forefinger "Don't worry about it."

A few days later, the executive director of the center, Joe McNulty, visited me. "Remember that guy Allen you met on the airline?" he asked. "He called me to find out if you made it back here O.K. Do you know who he is?"

"No," I said.

He was Allen Brill, the chief executive of Rolex USA.

A RIDE OF A LIFETIME

Reprinted from the winter newsletter of
the Earl Baum Center of the Blind
Santa Rosa, CA
By Leslie Bailiff, MA, COMS
& Jennifer Frazier

Jose Infante has been a student at the Earle Baum Center (EBC) for the past four years. Being deaf and severely visually impaired, Jose uses American Sign Language (ASL) to communicate. When he began services at the EBC, his sight was quickly diminishing. Jose worked hard as he studied braille and independent living skills with Denise Vancil, technology with Jennifer Frazier, and mobility with Leslie Bailiff. He has always been determined to do whatever he can to be both productive and live independently.

With the great improvements of adaptive technology, Jose discovered a new world. He is able to combine the use of a specialized note taking device called the BrailleNote that has a braille display and a synthesized voice together with Sendero Group's Global Positioning System that offers information which was previously only a dream. He now knows where he is located at any given time, whether walking or in a vehicle. He can find out how to get to a store or destination which is mapped out and spoken to him via BrailleNote. He can be given a description of landmarks and towns when in a vehicle and can even have the notetaker speak to others after he inputs the words by typing them onto the unit.

One Saturday, Jose rode the bus from Santa Rosa to Cloverdale using his GPS (an adventure since he rarely travels long distances). In Cloverdale, at his brother's home, everyone gathered around to see his new machine. Jose played a typed message to his family. After hearing Jose's message the family typed a reply which Jose read in braille. This trip went so smoothly that Jose has developed a newfound confidence to travel on his own.

We are very excited to see Jose learn so much that allows him to live a normal life. With technology and hard work, people who are deaf/blind are much less isolated and are able to integrate into daily activities.

In Jose's words (Jose's first language is ASL), he describes the process of getting trip directions to Community Resources for Independence using the GPS:

"GPS is great! I like to learn my Braille-Note (note taking machine) with GPS and training. I typed to answer Control + S for address looking, state: California, city: Santa Rosa, name street: Hopper Avenue., and number street: 980 entered, then press R and P for walking press Control + T left turn on Range Ave. to North then heading 1 miles and left turn on Piner RD to West. Then Right turn on Airway Dr heading to North, then on Hopper Ave. at CRI, 980 Hopper Ave. The End."

Note: The BrailleNote has been specifically designed to provide visually impaired people a portable word processor, Internet access, email and wayfinding technology. This is a specially designed personal data assistant. The BrailleNote provides both braille and speech feedback to a blind person.

2005 BHTA INDEPENDENT LIVING DESIGN AWARD WINNERS ANNOUNCED

From Press Release Issued by
HumanWare Europe

The world's smallest portable personal digital assistant for blind people, that gives access to the internet, translates all information into braille and provides users with Bluetooth global positioning satellite navigation, has won first prize in the 2005 British Healthcare Trades Association (BHTA) Independent Living Design Awards.

A trophy was given to HumanWare, suppliers of the BrailleNote PK GPS by Angela Rippon at a ceremony at the House of Commons in November, 2005. The awards, now in their 11th year, were judged by six experts in the field of healthcare and assistive technology. All money raised from the awards is in support of the charity Phab. The judges had to choose from a large number of product entries on the criteria of being innovative, of good design and which make a real difference to users. (Assistive technology products help elderly and disabled people, eg. wheelchairs, stairlifts and walking sticks.)

The BrailleNote PK GPS from HumanWare incorporates a braille keyboard and 18 cell braille display. Utilizing an M/S Windows C.E. platform, users can read and respond to e-mails and surf the web. A compact flash card slot allows for additional data storage. It runs on AC power or batteries, and since it doesn't have to drive a visual screen battery life can last 20 hours or more. Users can read e-books and listen to their MP3s in stereo. The GPS tells the user exactly where they are when they're out and about.

BrailleNote PK GPS user John Gallagher, a piano technician from Rothwell, Leeds, is 51 years old and has been blind from birth. He went to a school for the blind, Tapton Mount School in Sheffield - he knew David Blunkett - then moved to the Royal National College for the Blind. John used to use a laptop with speech on it but has had a BrailleNote PK GPS since last April, which he says is much smaller and more portable.

Says John: "One of the great things about it is the global positioning. I have to travel all over Yorkshire and to different dealers in Cambridge and it helps me get around from A to B - I just put in the address where I'm going and it does the rest. If I'm on a train or a bus I can find out where I am and pinpoint when to get off. The internet ability is great too - I can go on email and use the web like any one using the Braille output on the screen. I also use compact flash cards which carry useful data, such as maps of Britain.

Contact Details:
HumanWare Europe
3 Blotts Barn Business Centre
Brooks Road, Raunds
Northamptonshire

NEW FROM FREEDOM SCIENTIFIC - FaceToFace

Submitted by Isaac Obie

FaceToFace allows a person who is deaf-blind to communicate with a sighted person using a PAC Mate and an iPaq. When a person who is deaf-blind has FaceToFace installed on an iPaq and a PAC Mate, when the iPaq is given to a sighted person and turned on, a message appears on the iPaq informing the person that conversation will take place using the iPaq and telling the person how to start the conversation.

The person can enter text into the iPaq using a small keyboard called a thumb keyboard, which is very convenient to use and carry with the iPaq, or, if the deaf-blind person doesn't want to carry the thumb keyboard, the user can input text on a virtual keyboard on the iPaq screen using a stylus to tap the characters to be entered. The text that is sent appears immediately on the PAC Mate and is identified as coming from the iPaq. When the PAC Mate user enters text, it appears on the iPaq screen and is identified as coming from the PAC Mate.

The FaceToFace conversation between the iPaq and the PAC Mate can be saved as a text file for future reference, also, contacts and calendar information and information from other files can be copied and pasted into the FaceToFace conversation to be transmitted automatically when it is pasted.

The entire Face-to-Face package costs $1,400. FaceToFace will work with both the PAC Mate BX and QX and will also allow communication between two PAC Mates if the FaceToFace application is installed on both PAC Mates.

For more information contact Freedom Scientific at 1-800-444-4443 or visit www.freedomscientific.com

EMPOWERING A DEAF-BLIND WOMAN

By Diane Lisanti, TTCS, New York City

Reprinted from The Source, newsletter of the Taoist Tai Chi Society, U.S.A.
Winter-Spring 2005

Michelle Smithdas teaches braille at the Helen Keller National Center for Deaf-Blind Youths and Adults on Long Island where I used to work. She is deaf-blind and has balance problems. Last August, we started a class with other hearing staff members. Michelle loved it and is the sole remaining member. We are up to the first Single Whip.

We have had to divide it up into small segments. We communicate through tactile sign language and have made up different names for some of the moves to make them easier to understand. The three parts of Grasp Bird's Tail, for example, are "throw away," "palm to palm," and "push Diane."

Michelle works with Diane on her Tai Chi positions

We started with the feet. I had her feel my feet and she would mimic them with her hands. Then she would stand up and do it. I used my foot to make sure her feet were as close as possible to the 45/90 degree Tai Chi stance, all the while holding her so she wouldn't fall.

To teach her what the hands do, I had her stand in back of me and feel my arms. That took quite a while. She said I had to help her to relax because she tends to be tense. The biggest problem is that blind individuals don't have any sense of location. You can't tell them to face the wall. What wall?

After about three months, Michelle didn't rely on me holding her as much. In class last week, she told me that she was bragging to her friends how Tai Chi has helped her balance, and how much fun it is for her to learn it.

Michelle says that she feels empowered doing Tai Chi. When she practices at home, she practices facing her bed. She says that way, if she falls over, it's just on to the bed.

The good thing is that Tai Chi makes sense tactually. If you had to verbally describe every move, you'd never get any Tai Chi done. Teaching Tai Chi to Michelle has taught me that it can be for everyone. I don't treat deaf-blind people any differently than anyone else, and it's great that the Taoist Tai Chi Society has the same philosophy.

People are not different in terms of their personal needs and Taoist Tai Chi will permit a person to do whatever they are able to do within the form - and it's okay!

MICHELLE'S PERSPECTIVE:

I learned about Taoist Tai Chi from HKNC's in-house weekly paper IN-TOUCH. Since I love any exercise that strengthens and helps to improve my muscles and bones, I inquired about the program. Since

I am deaf-blind and have a balance problem, it was decided that the best way for me to benefit from the Tai Chi classes was to be taught individually. Thus, the instructor would be able to fully concentrate on me and help me as much as she could. The instructor, Diane, was working at the HKNC as a case manager, so we agreed on having one lesson each week.

When I first began learning Tai Chi, I had no idea what it was, or what the activity involved. I was concerned about my balance, but I was not going to let that interfere, as I had taken yoga workshops in England; and I was determined to learn and succeed. Diane did not show me more steps and movements until I had mastered the present ones she was teaching me. This helped me to remember each step without being able to see them.

She allowed me to tactually feel her arms and feet when moving and would communicate the steps to me by fingerspelling or using ASL. Later she got the idea of using empty shoes to help make it easier to feel and follow through. Soon we noticed that the exercises were improving my balance.

Today, the problem I face is how to continue the program without Diane's guidance since she no longer works at HKNC, but I try to practice on my own.

I am hoping to find another Taoist Tai Chi instructor so I can continue. However, my recreational activities are not limited to Tai Chi — I also love swimming and using the exercise bike and the rowing machine. I may start using a treadmill soon.

My advice to anyone interested in

learning Tai Chi is that they should be optimistic and not give up the pursuit after just one or two tries. As with any recreational activity, it helps if you can find a small group for practice. Even better, it is helpful if you can work one-on-one with someone who has a similar interest.

VISION OF THE FUTURE

By Nara Schoenberg

Reprinted from the Chicago Tribune

June 2005

Being deaf and blind hasn't stopped Maya Eldar from climbing a 40-foot wall, learning prayers in Hebrew or graduating from high school. It has, however, been a major obstacle to finding a job.

Eldar, 23, of Skokie, has searched for work - any work - for more than a year, but so far all that she, her mother and the state of Illinois have been able to find is 10 hours a week folding laundry at a local nursing home. That's not enough, Eldar says in sign language, her long, nimble fingers tracing arcs in the air. "It feels bad not to work," she says.

At a time when many severely disabled people are graduating from mainstream schools with mainstream goals, Eldar's story is an increasingly common one. Only 35 percent of disabled people are employed, according to a 2004 Harris Poll, and the problem is worse for the severely disabled, a category that includes the estimated 70,000 Americans who are deaf-blind. Experts blame factors ranging from a tight job market to state budget woes to apathetic politicians.

Other aspects of the issue are as old as Helen Keller, the deaf-blind woman who published a best-selling autobiography while still a college student, provoked comparisons to Shakespeare and Napoleon, and struggled to find a paying job.

Deaf-blind people can work, says John Mascia, executive director of the adult rehabilitation facility at the Alabama Institute for the Deaf and Blind. He says he knows a deaf-blind lawyer and a veterinarian, as well as people who work in food services, computer programming and retail. Still, he says, for the most part the services that deaf-blind people need to hold a job - transportation and sign-language interpreters, for instance - are not available. "What's our commitment as a nation to people who deserve to live among us?" asks Mascia. "What's our responsibility to those less fortunate folks out there? And, deaf-blindness, boy, if you had to make a disability a poster child for that issue, deaf-blindness is a great one to use, because I don't know of any other disability that's more frightening to all of us."

Standing 4 foot 7, with short-cropped hair, leg braces due to cerebral palsy, and glasses that enhance a trace of vision in her right eye, Eldar seems frail at first, but that impression doesn't last long. Smiling frequently and reaching out to hold the hand of a new acquaintance, she launches into a series of eager questions, asked in sign language and translated by her mother, Faye Manaster, who signs back the answers under Eldar's hand, so she can feel the words forming. "Where do you work?" Eldar wants to know. "Is there an elevator?" "Who is your boss?" "Do you have children? A dog?"

Having attended elementary school with seeing and hearing children, Eldar is in many ways the leader in social situations. She is accustomed to putting others at ease. In other ways, though, she lives like a child, unable to go anywhere unaccompanied. Although she reads braille, knows thousands of words in sign language and has some light and form perception in her right eye - enough to see whether a door is open or shut – she can't speak, use a telephone, call for help among hearing people or walk alone on her own street. Even at best, her conversations are often filtered through her mother - not an ideal situation for a woman in her 20's - or through people who are not fluent in sign language.

That leaves Eldar, a lively and outgoing person, with limited opportunities to communicate fully and freely. "I'm bored," she signed to her mother during an interview at their modest red-brick townhouse, during which she repeatedly asked to go to the mall. "I know," Manaster signed back, nodding resignedly.

The odds are against Eldar, but then, they always have been. Born at 26 weeks and weighing only 1 pound, 9 ounces, she wasn't expected to live. Doctors said she was blind, but her mother, a former special education teacher, pressed for more tests. "There's something else wrong with my baby," she said.

At age 1, Eldar was found to be deaf

and to have cerebral palsy, a condition affecting muscle coordination. All her disabilities were caused by prematurity. Her first word, at age 1 1/2, was "hat," a sign that looks like what it means. "She knew if she was putting on a hat she was going out, so she was happy," her mother says.

Yet some of the most commonplace milestones of childhood - the tooth fairy, Saturday morning cartoons - were beyond her. Eldar couldn't watch TV, so she never begged for a well-advertised cereal. She understood Mickey Mouse and Big Bird only when she went to birthday parties and had hands-on encounters with people in animal costumes. "There's a person who has on a costume and the name is Mickey Mouse," her mother would say.

Under the Individuals with Disabilities

Education Act, which in 1975 revolutionized education for the disabled by guaranteeing a free and "appropriate" education, Eldar was entitled to a variety of specialized services and she made the most of them, at one point racing ahead two years in nine months.

When it came time for her bat mitzvah, a Jewish coming-of-age ceremony, she had to study religious texts in braille, sign language and English, and to sign prayers in Hebrew. "It's a major thing. It's a really major thing for someone to do," says her rabbi, Douglas Goldhamer of Congregation Bene Shalom, a synagogue serving the deaf. "And she did a bang-up job."

At John Hersey High School, Eldar participated in work programs, making ice packs for the school nurse, packing test tubes for a laboratory, doing light clerical work and packing items. "Maya's a fighter," says her father, Arthur Eldar, 58, a vocational school director, who is divorced from Manaster but remains close to his daughter. After graduating in 2002, Eldar spent some time at the Helen Keller National Center in Sands Point, NY. During her stay there, she learned independent living skills such as communicating with hearing co-workers, using a book with short statements such as "more work, please," written in both English and braille.

She participated in recreational programs and lived with other deaf-blind people in a relatively independent dormitory setting. "The Center is like the Garden of Eden for people who are deaf-blind," Manaster says. "The barriers are gone. You're able to freely communicate with just about everyone there."

Eldar returned to Skokie excited about her future and eager for a job. That's when her problems began, her mother says. For more than a year, her mother has pressed state-funded agencies to find work for her daughter, with little success. The nursing home job Eldar does have is the product of a search by her rabbi, and her hours were only increased from four hours to nine in March.

"I felt mad and frustrated to wait and wait and wait," she says. Manaster thought the money allocated to Eldar by the state - potentially more than $41,000 a year - should have been used for a job search and job support rather than the adult learning program for the disabled that Eldar attended, reluctantly, three days a week for a year and a half. There, she was grouped with severely disabled people who didn't sign, meaning she couldn't talk to them. Even the staff members weren't fluent in sign language.

"I want to quit the day program. It's boring," she says. Why? She was asked. "I don't have friends." Were the people nice? "No, they can't communicate with me." Tom Green, a spokesman for the Illinois Department of Human Services, referred questions about Eldar's job search to the two agencies the state pays to serve her directly, Clearbrook of Arlington Heights and Community Alternatives Unlimited of Chicago. Officials at Community Alternatives Unlimited did not return phone calls from the Tribune.

Carl La Mell, the president of Clearbrook, which provided Eldar's adult-learning program, said his agency was never supposed to do a job search for Eldar; that wasn't part of Clearbrook's contract with the state. In an interview in October, La Mell said that it would be great if Eldar could work more hours, but, given the limited money available to help the severely disabled, that wasn't "necessarily a priority" for his agency. "At least she has a place to go and she's being served very well," said La Mell. "There are hundreds, if not thousands of people who are not getting services at all."

Experts say that services for the severely disabled are spread thin nationwide. David Braddock, the executive director of the Coleman Institute for Cognitive Disabilities at the University of Colorado, also points to problems specific to Illinois. One of the wealthiest states, Illinois ranks 42nd for the percent of personal income allocated for community services for the mentally retarded and developmentally disabled, according to a study co-authored by Braddock. "The state of Illinois has simply not attached high priority to services for people with developmental disabilities, ever," Braddock says. "It's an issue that's been chronically underfunded, chronically not a priority in the state, chronically the subject of political infighting," with none of the top politicians being willing to spend political capital on the issue.

Eldar, who climbed a 40-foot wall as a teenager with the help of a camp counselor, continues to tackle new challenges. She's taking classes in dog massage, which she hopes to eventually make a career. For Mother's Day, she had her mother take her to Dominick's so that she could buy flowers: "I'll smell all the different flowers and pick the ones that smell the best to me."

But without the challenge of living independently, as she did at the Helen Keller Center, Eldar has in some ways moved backward in the past year and a half, Manaster says. "She's regressed in many areas of her independent living skills and it hurts as a mother to see that. It hurts." Manaster, who estimates she spends 15-20 hours a week advocating for her daughter, keeps fighting. She recently set up an advisory council of friends and community members to help Eldar find more work and live independently.

But at times, even Manaster sounds tired. She says she has taken pay cuts over the years to care for her daughter, and her own arthritis makes it difficult to do the heavy lifting involved in caring for Eldar. Manaster worries about the possibility of a county property tax increase, and she worries about her daughter's future: "If something happens to me, she could end up in a nursing home or an institution."

Eldar sometimes seems anxious, asking numerous questions, for instance, when her mother has to have a medical test. But she is firm and calm as she maps out her vision of the future: a job, an assistance dog and an apartment of her own, with support staff to help her live independently.

"Where do you want to live?" her mother asks. "Skokie."

"You want to get a new apartment with staff too?" Eldar, answering yes, whisks her thumb forward against her right jaw: "Tomorrow." Her mother frowns. "It will not be tomorrow. I'm sorry."

In theory, disabled people seeking work in America have numerous rights. The Americans with Disabilities Act forbids companies with 15 employees or more from discriminating against the disabled in hiring or employment and requires, in many cases, that employers make reasonable accommodations such as installing ramps or hiring sign language interpreters.

States such as Illinois have similar laws covering smaller employers. But in practice, it's very hard to prove that you've been denied a job because an employer doesn't want to pay for a reasonable accommodation, according to Robin Jones, the director of the Great

Lakes ADA Center, a federally funded agency assisting the disabled.

The prospective employer has no obligation to hire a qualified disabled person over other qualified applicants. "The ADA is not an affirmative action law," Jones says. Even if you can prove discrimination, you may not be able to afford a lawyer. State and federal funding for legal assistance to the disabled is "pretty limited," according to Tony Paulauski, the executive director of the Arc of Illinois, which advocates for the disabled.

Similarly, the law - in this case the Rehabilitation Act of 1973 - mandates vocational services to help disabled people seeking employment. But the Rehabilitation Act doesn't entitle disabled people to specific services, Jones says.

States have discretion in key areas, and factors such as a state's assessment of a person's potential for employment and the amount of tax money available can determine what kind of help people get.

Medicaid, which is federally funded and run by the states, theoretically pays for workers to assist disabled people in living independently. But, while technically an entitlement program based on income and disability, Medicaid is, in practice, contingent on state funding.

In states including Florida, Massachusetts and Washington, the disabled have sued, with some success, to reduce the wait for Medicaid services, arguing that, under federal Medicaid law, those eligible for benefits must be served with "reasonable promptness."

In Illinois, advocates recently succeeded in getting the state legislature to approve a 3 percent increase in the amount of money community organizations get from the state, but a proposal for a 50-cent-per-hour salary increase for workers serving the disabled did not survive the state budget process.

That leaves starting salaries at about $9 or $10 an hour, not nearly enough to attract and keep qualified staff, according to Paulauski. "The system is so underfunded" and has been for years, says Paulauski, who cites a study at the University of Colorado that ranked Illinois 46th among the states.

"What you really need to do is have salaries that are similar to teachers,'" Paulauski says. "When you're talking $10 or $11 an hour, you're not even close."

ON NEW YEAR'S EVE

By Robert J. Smithdas

I have resolved that this will be
a year that's resolution-free:
I will avoid the old mistake
of pledging vows that I will break
because the devil tempted me.

Instead, I'll follow destiny,
and learn a new philosophy;
I'll do my best while wide awake,
I have resolved.

Life is such a mystery
of hope and joy and tragedy.
I know the future is opaque,
but I will strive, for heaven's sake,
to lead a life of quality
I have resolved.

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